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A Historical Analysis of the Pioneers and Advocates of Autism Spectrum Disorder (1980-2013): Examining the Evolution of the Diagnosis and the Influences That Have Shaped What the Diagnosis Is Today

Cynthia Marie Sikora
Loyola University Chicago

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LOYOLA UNIVERSITY CHICAGO

A HISTORICAL ANALYSIS OF THE PIONEERS AND ADVOCATES OF
AUTISM SPECTRUM DISORDER (1980-2013):
EXAMINING THE EVOLUTION OF THE DIAGNOSIS AND THE INFLUENCES
THAT HAVE SHAPED WHAT THE DIAGNOSIS IS TODAY

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL OF EDUCATION
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF EDUCATION

PROGRAM IN ADMINISTRATION AND SUPERVISION

BY

CYNTHIA SIKORA

CHICAGO, ILLINOIS

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and being willing sounding boards and beacons of encouragement throughout this entire process.

DEDICATION

I dedicate this dissertation to my parents, my husband and my children. You have all been a part of making me who I am today and without your love and support I would be nothing. I love you and I am beyond blessed to have you with me to share in this journey.

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ABSTRACT

During the 1980's, Autism Spectrum Disorder (ASD) was categorized as a developmental disorder separate from other developmental disorders, in the Diagnostic and Statistical Manual of Mental Disorders III (DSM-III). There were various pioneers and advocates who have helped the evolution of the ASD diagnosis from the time period of 1980-2013. Based on this evolution, schools, institutions and society as a whole, needed additional information and professional preparation in order to educate and create awareness regarding the treatment and education of individuals with ASD.

The central research questions are: During the time period from 1980-2013, who were the pioneers and advocates for the medical field, assessments, therapies and educational treatments, regulations, rights, funding and societal acceptance for ASD? By what means did they advocate, and what role did their advocacy play in the evolution of diagnosis? How did the changes in each of the above mentioned areas impact those with ASD? What are the implications for today's educational leaders as advocates for educational programming, societal acceptance, care and respect for those with ASD?

This study concluded that many pioneers and advocates played an important role in the evolution of the ASD diagnosis. Each pioneer and advocate, in their own regard, increased awareness and contributed to the way ASD is perceived. This awareness has changed how people with ASD are educated and treated today.

CHAPTER I

INTRODUCTION

Purpose of the Study

During the 1980's, Autism Spectrum Disorder (ASD) was categorized as a developmental disorder separate from other developmental disorders, in the Diagnostic and Statistical Manual of Mental Disorders III (DSM-III). Based on this classification, schools, institutions and society as a whole, were in need of additional information and professional preparation in order to educate and create awareness regarding the treatment and education of individuals with ASD. As time progressed, the number of individuals who received the diagnosis of autism increased (Steuernagel, 2005).

By 1990, there was a rapid increase in the diagnosis of ASD (Steuernagel, 2005). This progression in the number of individuals diagnosed with ASD then led to the need, in 1994, for the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) to alter the definition of ASD and expand it to include Asperger's Syndrome. Asperger's Syndrome is considered a higher-functioning form of autism, as well as progressive developmental disorder (Mandlawitz, 2002). The need for an expanded definition of autism was necessary because the umbrella under which the diagnosis was developed varied greatly regarding the area of cognitive functioning. The expansion of the definition gave a broader picture regarding the needs of a person diagnosed with autism, while also redefining what the American Psychiatric Association considered the correct identifying markers. The expansion of the definition also helped redefine the diagnosis

for people in the medical and educational fields to more effectively treat and assist these individuals. This redefined diagnosis, also helped to identify the need for further funding, and helped in clarifying the regulations and rights pertaining to these individuals.

According to Autism Speaks Inc. (2009), the diagnosis of ASD has increased from identifying one in every 150 children in 2007 to identifying one in every 110 children in 2009. This drastic increase in the ASD diagnosis, over a relatively short time period, has caused school and community leaders to question, the possible causes for this increase, and also investigate where this diagnosis is headed in the future. The inquiry regarding what caused the rise in the diagnosis, has taken place, in part, because of the drastic increase in number identified. The inquiry is also due to the influences and changes in the medical field, the assessments used for diagnosis, the changes in therapy and educational treatment for ASD, plus the evolution of increased rights, regulations, funding and societal acceptance. All of these factors have contributed to evolution of the diagnosis of ASD, and because of this, there is a need to understand the role played by each factor in this evolutionary process. In order to understand this process, certain areas will be studied. Changes in the medical field, the assessments used for diagnosis, the changes in therapy and educational treatment for ASD plus the evolution of increased rights are one set of areas. Changes in regulations, funding and societal acceptance over time are another set. The roles that pioneers and advocates have played in these changes are another set. Once these areas are addressed, the information will chronicle the history

of the ASD diagnosis over the last 30 years, and demonstrate an improvement in the understanding and increased awareness of autism?

The purpose of this study was to examine the evolution of understanding of ASD from 1980-2013. Specifically, this study identified: (1) pioneers and advocates for change in the areas of medical diagnosis and treatment of ASD, (2) pioneers and advocates for change in assessments of ASD, (3) pioneers and advocates for change in therapies and educational treatments of ASD, and (4) pioneers and advocates for change in the regulations, rights, funding and societal acceptance of people with ASD. The methods of advocacy were determined, as well as the impact of the advocated changes on those with ASD. Additionally, this study explored the implications for educational leaders as advocates for educational programming, societal acceptance, care and respect for people with ASD.

Significance of the Study

As of 2013, according to Autism Speaks Inc. (2013), the diagnosis of ASD has increased to a staggering one in 88 children and one in 54 males. Autism Speaks Inc. is an organization that was started in 2005 for the purpose of increasing awareness and advocacy for ASD. Its founders, Bob and Suzanne Wright, started the organization to help their grandchild who was diagnosed with autism. Because of their great work, Autism Speaks Inc. is now one of the world's leading organizations in autism science and advocacy and has helped to increase awareness of ASD. Due to the increase in diagnoses over the years, it is critical for American society to become more aware of the needs of individuals with ASD and how this diagnosis has reached these staggering heights. The

knowledge that has been gained from evolution of ASD has influenced the way society at large and educational leaders in particular treat, educate, fund and regulate individuals with autism. This study identified and described the evolution of ASD from 1980 to 2013 and its impact on autism and the diagnosis of autism.

One major area that the diagnosis of ASD affects is special education in American school systems. Special education is considered one of the most important means of addressing the individualized educational needs of students with ASD. Students diagnosed with ASD receive services under the umbrella of special education. This means that students' educational needs require individual attention from schools and other educational institutions. Educational policies and practices have changed over time, due to the changes in the areas of medicine, assessment, therapies and educational treatments and regulations, rights, funding and societal acceptance. Additionally, practices have evolved regarding how students with ASD are educated within the classroom. Accommodations for students with ASD are examples of how educational programming has changed due to the revisions in ASD. Some changes that have evolved from accommodations are the need for students with ASD to be involved in regular education socialization within the classroom, the need for restructured environments for learning in the classroom, the need for exceptions for students with ASD regarding time constraints on homework, and the need for restructured test-taking provisions for these students. In order to make gains that will benefit students with ASD, school systems will need to continue to improve the academic and therapeutic delivery systems they use and address the social needs and interpersonal skills of these students. Perhaps if this

improvement continues to be the focus of school systems for students with ASD, educational programs may improve each year, and so may the opportunities for students with ASD to make a healthy and productive transition into adult society.

This study examined the change in society's view of individuals with ASD from 1980-2013. Such changes in thought have influenced the quality of productivity from these individuals in society and what the future holds for their care and the degree of respect they will receive. This study discussed the implications for today's educational leaders as advocates for educational programming, societal acceptance, care and respect for those with ASD.

Research Questions

In order to examine the evolution of ASD and the roles that pioneers and advocates have played in the growth of awareness of ASD, this study answered the following research questions:

- 1a) During the time period from 1980-2013, who were the pioneers and advocates in the medical field for ASD?
- 1b) By what means did they advocate, and what role did their advocacy play in the evolution of diagnosis and medical treatment?
- 1c) How did the changes in the medical field impact those with ASD?
- 2a) During the time period from 1980-2013, who were the pioneers and advocates in assessment for ASD?
- 2b) By what means did they advocate, and what role did their advocacy play in the evolution of assessment?

- 2c) How did the changes in assessment impact those with ASD?
- 3a) During the time period from 1980-2013, who were the pioneers and advocates for therapies and educational treatments for ASD?
- 3b) By what means did they advocate, and what role did their advocacy play in the evolution of therapies and educational treatments?
- 3c) How did the changes in therapies and educational treatments impact those with ASD?
- 4a) During the time period from 1980- 2013, who were the advocates for increasing the regulations, rights, funding and societal acceptance of ASD?
- 4b) By what means did they advocate, and what role did their advocacy play in the evolution of increased regulations, rights, funding and societal acceptance?
- 4c) How did the changes in increased regulations, rights, funding and societal acceptance impact those with ASD?
- 5) What are the implications for today's educational leaders as advocates for educational programming, societal acceptance, care and respect for those with ASD?

Methodology

The methodology for this study was historical documentary research. Historical documentary research is the recognition of a historical problem or the identification of a need for certain historical knowledge (Creswell, 2008). This study fulfilled the criteria for historical documentary research because the significance of past research in the area of

the medical field, assessments, therapies and educational treatments, and regulations, rights, funding and societal acceptance regarding ASD, validated change and impact of a significant period of time. Creswell discussed how, without reviewing historical documents in research, the true picture of the origin of a topic is never truly realized. Using historical research, gives an opportunity for the researcher to reveal to the reader a sense of historical renewal for a given topic. According to McCulloch (2004), researchers should examine historical documents to study people and their motivations, and then, use those findings to enlighten others regarding contemporary issues. Johnson and Christensen (2004) had similar views as they stated, “historical research is more than just a retelling of past facts, but it is a fluid and dynamic account of past events that attempts to recapture the complex nuances, individual personalities, and ideas that influence the events being investigated” (p. 391).

By examining the historical changes in the medical field, assessments for diagnosis, therapies and treatments, and rights, regulations, funding and societal acceptance that were responsible for dynamic change in ASD, the researcher revealed a new account of what evidence we have that has shaped the diagnosis of ASD and how people viewed it as a disability in 2013. The historical perspective revealed how advocates and pioneers made great gains over the last 30 years in these areas and how these gains affected the education and socialization of individuals with ASD.

Primary and secondary sources were used to delve more deeply into the details of these events. These sources illustrated how changes and important events have become the vehicles by which the ASD diagnosis has been enhanced over the last 30 years.

Primary sources are comments written by people who were directly related to the event and/or present at the event being studied (Creswell, 2008). This study utilized primary sources to reflect evidence of the evolution over time in the medical field, assessments, therapies and educational treatments and regulations, rights, funding and societal acceptance. Evidence was retrieved for each of these areas via primary sources such as established medical evidence and studies, effective treatment protocols, enacted legal regulations which have been helped develop regulations, rights, funding and societal acceptance and statutes and reports of these regulations. Specific changes to the diagnosis itself were provided from primary sources such as the Diagnostic and Statistical Manual of Mental Disorders (DSM). Secondary sources such as journals, articles, medical journals and articles along with reports were utilized to reflect the changes and evolution over time in the medical field, in assessments, in therapies and educational treatments and in regulations, rights, funding, and societal acceptance as well as to demonstrate the second hand accounts and opinions of these historical milestones. Secondary sources, however, are written after the event has taken place by people who were often times not directly related to the event. However, these writers can still have direct historical significance (Creswell, 2008). Sometimes sources fall under both categories, but this was stated by the researcher, in order to better clarify which part of the source is declared primary and which is declared secondary.

Websites, such as the one produced by Autism Speaks Inc. were used as primary and secondary sources to support the findings and to add to the media and technological evidence.

Limitations to the Study

Biases of Researcher

1. In the professional experience of the researcher, the researcher has observed ineffective application of therapies and educational treatments, as well as educational programming.
2. The researcher is aware that the need to put personal experience and context aside is critical, as it may cause the researcher to look for particular outcomes, which could result in missing key conclusions from the research.
3. The researcher's experience in assessments, therapies, educational treatments and educational programming could impact objectivity.
4. The researcher is a Speech-Language Pathologist working with students who were diagnosed with Autism Spectrum Disorder (ASD) in a public high school.

To control for the above mentioned biases, the researcher maintained researcher objectivity by:

Keeping a reflective journal. The researcher wrote reflections about the incidents or literature that caused the loss of objectivity. Being that part of the researcher's daily work involved assessment, therapy, educational treatment and educational programming of students with ASD, the researcher needed to constantly be aware of these biases.

Definition of Terms

The Diagnostic Criteria for Autism Spectrum Disorder in the DMS-5-Autism Spectrum Disorder 299.00 (F84.0)

Diagnostic Criteria

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
 4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse

response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals, who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) **(Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.) (American Psychiatric Association, 2013, p. 50).

Pervasive Developmental Disorders-Definition in DSM-IV prior to changes in DSM-5

Autistic Disorder:

(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) qualitative impairments in communication as manifested by at least one of the following:

1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(A) social interaction

(B) language as used in social communication

(C) symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (American Psychiatric Association, 2000, p. 75)

Pervasive Developmental Disorder-Otherwise Not Specified (PDD-NOS):

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria

are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" --presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these (American Psychiatric Association, 2000, p. 84).

Asperger Disorder (Asperger Syndrome):

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1. marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2. failure to develop peer relationships appropriate to developmental level
 - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - 4. lack of social or emotional reciprocity
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - 4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia (American Psychiatric Association, 2000, p. 84).

Rett's Disorder (Rett's Syndrome):

- A. All of the following:
 - 1. apparently normal prenatal and perinatal development
 - 2. apparently normal psychomotor development through the first 5 months after birth
 - 3. normal head circumference at birth
- B. Onset of all of the following after the period of normal development:
 - 1. deceleration of head growth between ages 5 and 48 months
 - 2. loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (i.e., hand-wringing or hand washing)

3. loss of social engagement early in the course (although often social interaction develops later)
4. appearance of poorly coordinated gait or trunk movements
5. severely impaired expressive and receptive language development with severe psychomotor retardation (American Psychiatric Association, 2000, p. 77)

Childhood Disintegrative Disorder:

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
 1. expressive or receptive language
 2. social skills or adaptive behavior
 3. bowel or bladder control
 4. play
 5. motor skills
- C. Abnormalities of functioning in at least two of the following areas:
 1. qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
 2. qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
 3. restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms
- D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia. (American Psychiatric Association, 2000, p. 79)

Eugenics - “Eugenics is the science which deals with all influences that improve the inborn qualities of a race” (Galton, 1904, p. 1).

Individuals with Disabilities Education Act (IDEA) Part C - (see Appendix A)

Thimerosal - Thimerosal is a mercury-containing preservative used in some vaccines and other products since the 1930's. There is no convincing evidence of harm caused by the low concentrations of thimerosal in vaccines, except for minor reactions like redness and swelling at the injection site. However, in July 1999, the Public Health Service agencies, the American Academy of Pediatrics, and vaccine manufacturers

agreed that thimerosal should be reduced or eliminated in vaccines as a precautionary measure. Today, all routinely recommended childhood vaccines manufactured for the U.S. market contain either no thimerosal or only trace amounts with the exception of some flu vaccines. There are thimerosal-free influenza vaccines available (Center for Disease Control and Prevention, 2013a).

Vaccine - A product that produces immunity therefore protecting the body from the disease. Vaccines are administered through needle injections, by mouth and by aerosol (Center for Disease Control and Prevention, 2013b).

Overview of Chapters

The following is a summary of chapters. Each chapter is described by giving details regarding the framework of each chapter and the pieces of evidence supporting the specific factors important to the evolution of ASD.

Chapter I introduced the study itself. It explored the purpose of the study, as well as included the proposed research questions, definition of terms, summary of proposed chapters and the methodology.

Chapter II is a background on special education and the diagnosis of Autism Spectrum Disorder (ASD) prior to 1980. The chapter examined how the pioneers and advocates of this time worked from the 18th century through the 21st century to help individuals with special needs to receive the educational services they deserved. Chapter II also discussed ASD and the pioneers and advocates who discovered ASD, and how they have helped to influence the evolution of ASD prior to 1980.

Chapters III through VII explored some of the current pioneers and advocates for ASD and also described the many factors they have influenced and changed in the evolution of ASD from 1980-2013. The factors discussed in these chapters included the influences and changes in the medical field, assessments, therapies and educational treatments, regulations, rights, funding, and societal acceptance.

Chapter III discussed medical developments regarding ASD from 1980-2013, and the pioneers and advocates who influenced these developments. This chapter included such discussions as an overview of the lives and accomplishments of the two most renowned pioneers of all time in ASD, Leo Kanner and Hans Asperger. Chapter III included the work of Lorna Wing and a discussion of how she was influenced from her time spent with Hans Asperger. The chapter continued on to discuss the evolutionary influences of Margaret Bauman and her findings regarding the neurological components relating to the diagnosis of ASD.

In addition to the findings of these major pioneers and advocates, discussions regarding the changes in the Diagnostic and Statistical Manual (DSM) from the third edition to the proposed changes for the fifth edition were highlighted. The changes and influences of the DSM-III and DSM-IV included such details as revisions in terminology and diagnostic criteria of ASD, changes in the definition of Pervasive Developmental Disorder (PDD), Autistic and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), the inclusion of the Asperger's Syndrome diagnosis, and finally the more current exclusion of the individual diagnoses for autism and the change to one all-encompassing diagnosis in the DSM-5. These changes were discussed to demonstrate

the influences that these classifications of diagnosis have had on the identification of individuals with ASD and the related statistics.

Chapter III also discussed some of the discoveries in the research which determined the cause and/or neurological and biological markers thought to be critical in the identification of ASD from 1980 to 2013. These discoveries in research were discussed to reflect the influences of this research on the evolution of ASD. Such research discoveries included the possible influence of the maternal and paternal age on the fetus, neurological markers on the fetus, a possible genetic or a familial link to causation, and the possible prenatal signs and risk factors. Chapter III also included the controversial discussion concerning the role vaccinations have played in the diagnosis of ASD. This discussion included the study completed by Andrew Wakefield in 1998 regarding the use of Thimerosal in the Measles, Mumps and Rubella (MMR) vaccine, and how in 2002 his study was discredited.

All of these changes and influences in the medical field relating to ASD demonstrated how the medical field has played a role in the evolution of ASD and how the great pioneers and advocates, have had a hand in being catalysts for influence and change whether their influences were of a positive or negative nature.

Chapter IV discussed the different assessments that were created to make the diagnosis of ASD a more clarified and standardized process and the influences these assessments have had on the evolution of the ASD diagnosis from 1980 through 2013. The chapter included the following assessments: the Checklist for Autism in Toddlers (CHAT), the Diagnostic Interview for Social and Communication Disorders (DISCO)

formerly known as the Handicap Behavior and Skills (HBS), and the Childhood Autism Ratings Scale (CARS). Chapter IV also discussed the influences on the statistical increase in the diagnoses of ASD and what this increase has meant for the schools. Along with the specifics of what these assessments have contributed to the diagnosis process, the pioneers and advocates themselves were discussed in order to explore their reasoning for creating these assessments and what they gained from the creation of these diagnostic tools. The pioneers and advocates of these assessments included Simon Baron-Cohen (creator of the Checklist for Autism in Toddlers-CHAT), Lorna Wing and Judith Gould (creators of the Diagnostic Interview for Social and Communication Disorders-DISCO formerly known as the Handicap Behavior and Skills-HBS) and Eric Schopler and Robert Reichler (creators of the Childhood Autism Ratings Scale-CARS). Each of these pioneers and advocates has advanced a specific rationale for the development of each assessment and each rationale has had an influence on or has helped to change the diagnosis of ASD. The chapter concluded by explaining how these diagnostic criteria has affected the school systems and have helped to more effectively serve the educational needs of individuals with ASD and improve their ability to cope in society.

Chapter V discussed the pioneers and advocates who have helped develop the different therapies and treatments that have been used in the therapeutic setting, as well as in the educational setting from 1980 to 2013. In addition to the pioneers and advocates, this chapter also discussed the evolution of therapy and educational treatments and how their focus has changed over time from behavior modification, to a better

understanding of the need for social skills in the areas of social interaction and pragmatic communication.

Specific therapies and educational treatments for ASD discussed in this chapter are the Teaching, Expanding, Appreciating, Collaborating and Cooperating and Holistic (TEACCH) autism program, the Lovaas method, Social Stories, Social Thinking and the Gluten and Casein Free Diet. Each of these therapies and educational treatments is very well known, and each has been proven effective by their own research theories. The discussion of these programs included a narrative about the pioneers and advocates of each therapy and educational treatment. The creators of these therapies and educational treatments are Ole Ivar Lovaas (creator of the Lovaas method), Eric Schopler (creator of the TEACCH autism program), Carol Gray (creator of Social Stories), Michelle Garcia Winner (coined the term *social thinking* and developed educational therapy tools revolving around the concept of social thinking), and Kalle Reichelt (creator of the Gluten and Casein Free Diet). These programs were discussed to help reveal the rationale for the creation of these therapies and educational treatments, the effectiveness of each rationale and how each therapy and educational treatment has changed and influenced the evolution of ASD. The discussion of this evolution also aided in the creation of an improved understanding of how school systems have attempted to incorporate some of these therapies and/or educational treatments into their curriculum.

Chapter VI discussed the regulations, rights, funding and societal acceptance that have evolved from 1980-2013, along with the pioneers and advocates who have advanced this evolution.

One of the regulations discussed was the Individuals with Disabilities Education Act (IDEA), and how ASD was added as a category for reporting United States statistics concerning the utilization of special services within the schools, and also added to the categories of youth served under the Act. Another regulation that was discussed is the Charter of Rights of Persons with ASD. It was adopted as a written declaration by the European Parliament. The United States Congress also created the Executive Order on Community Based Alternative Treatment, No Child Left Behind (NCLB), and the Reauthorization of IDEA or Public Law 105-17, which mandated that a range of services be provided to infants and toddlers with disabilities, through what is now called *Early Intervention*. From the regulations discussed in Chapter VI also came an increase in the rights of individuals with ASD. Some of the major events that defined and increased the rights of individuals with ASD are events such as the World Health Organization officially recognizing ASD and publishing ASD in the International Statistical Classification of Diseases and Related Health Problems (ICD-9), the world's first Asperger's Syndrome Conference in London, the Supreme Court requiring states to provide community based treatments for people with disabilities under ADA, the ASD rights movement led by Jim Sinclair, and the United Nations declaring April 2nd as World Autism Awareness Day with the United States adopting this declaration as well.

With these regulations and rights declared, funding over time for ASD has also increased. The increased needs of individuals with ASD created the need for better programming and increased services. Some examples of the funding increases provided from 1980-2013 are the National Institutes of Health (NIH) contributing \$5 million

dollars toward autism research, the Combating Autism Act granting \$1 billion dollars in expenditures over five years to ASD in the areas of care and research, and President Obama pledging during his campaign that he will commit to one billion dollars of annual federal spending on ASD by 2012 because he identified ASD as one of his administration's top three public health priorities.

With more regulations and rights being developed to govern the treatment for individuals with ASD, a greater social acceptance of ASD occurred. This acceptance was especially notable during the period from 1980-2013. Celebrities played a very important role in this acceptance. Examples of this celebrity influence will be discussed in Chapter VI. Sylvester Stallone, Jenny McCarthy, and Tommy Hilfiger are some of the celebrities who have become very well-known for helping bring acceptance of ASD to American society through their discussions about their loved ones' struggles with ASD. In addition, the movie *Rain Man* proved to be a major turning point for societal acceptance of ASD. Due to the increase in celebrity discussions regarding ASD, an increase in awareness became evident in American society. This awareness has drawn interest in ASD, but it has also called people to action to provide increased services and research for those who struggle with ASD.

Chapter VII is the final chapter. This chapter compiled all of the information from the prior chapters and explained what the findings meant for today's educational leaders. All of the factors discussed in the prior chapters, have aided in the evolution of ASD. The influences and changes in the medical field, in assessments, in therapies and educational treatments, in regulations, rights, funding and societal acceptance have

implications for today's educational leaders as advocates for the societal acceptance, the care, and the respect for those with ASD. This chapter identified the need for further research and provided insight for today's educational leaders on how they, as leaders and advocates, can better prepare the educational system to effectively and fairly serve individuals with ASD.

CHAPTER II

BACKGROUND

Introduction

The need for special education originated over time from the need to help those who were different. Throughout history, people exhibiting social, political, intellectual or physical differences were usually met with little tolerance and declared to be substandard among social groups (Ritvo, 1976). The basic rights of people with these differences were generally ignored. It is through these historical records that the disabled began to find a voice with which to improve their education and overall existence. With great struggle, people with Autism Spectrum Disorder (ASD) have evolved from being classified as people who were mentally insignificant, to people who can and should be educated to become productive members of society. The many forms of historical documentation have afforded educators the opportunity to review history in order to measure the growth that individuals in society have experienced (Creswell, 2008). The specific individuals in society who will be examined in this research are individuals with disabilities, specifically individuals with ASD. Historical documentation has also helped educators to understand the origin of change in individual groups in society, so that future educators can continue to build an improved environment of equal opportunity for people with physical, mental, and/or emotional challenges.

Background of Special Education in the 18th Century

As far back as the 18th century, Britain and Europe began to develop a system of instruction for the disabled (Winzer, 1993). The French Enlightenment, or the *Enlightenment* as it was referred to, began to alter peoples' perspectives regarding those who were considered disabled by changing societal opinions. As time went on, these perspectives changed from opinions of judgment toward the disabled, to social consciousness (Chaves, 1977). Because of this movement, people in society, who usually did not attend to people who were different from themselves as human beings, began to take notice of the disabled, and recognized them as people who had special needs and who were in need of assistance. People who helped this issue become better known, were such historical philosophers as Jean Jacques Rousseau, John Locke, Voltaire (François-Marie Arouet), Denis Diderot, and Etienne Bonnot de Condillac (Chaves, 1977). It was a definite struggle for these philosophers to initiate change in the societal way of thinking regarding individuals with differences, but they persevered and championed this cause. These philosophers forged ahead due to their desire to foster change in the general perception concerning the disabled. This desire to alter the social mores regarding the disabled provided the disabled with opportunities for special education techniques and theories to become part of that change.

Locke (1689) discussed the ways that individuals think and how society, at that time, perceived the acquisition of knowledge in his essay, *The Two Treaties of Government*. His theories in his essay were two-fold. They taught society how the human mind acquires information, and at the same time, how individuals make

judgments about others. Jean Jacques Rousseau was also a philosopher who agreed with Locke's perspective as they shared the views that education should be approached from the perspective of how each individual learns, and not how society perceives them and/or how society believes they should acquire knowledge (Boyd, 1956). Rousseau's beliefs in the education of each individual led to the next big change in systemic instruction. This change began in the latter part of the 18th century, and it was meant to develop even more change for individuals with disabilities. At this time, social classes were being destroyed and a more fair and equal society was hoped for by many people (Winzer, 1993). From the desire for equality among people, special education for individuals with disabilities was starting to become a more acceptable topic. Actual schooling for these people was not yet the norm, but definite experimentation with instruction as a charitable cause became much more widespread (Levinson, 1965).

Background of Special Education in the 19th Century

As time passed, people with disabilities began becoming a point of interest to society, but topics such as classification of these individuals, and educational structures were still primitive in nature. Jean-Marc-Gaspard Itard was responsible for some of this progress at the end of the 18th century and at the beginning of the 19th century. He was responsible for caring for a mentally impaired boy he referred to as Victor (Itard, 1932). This young man became the face of disabled people for this time period because Itard took his knowledge from Locke (1689), and began working with this young man to help him strive for a more normal lifestyle. Itard eventually became humanized by the

experiences that he had with Victor, which then went on to help to prove that people with disabilities could be educated.

Even though the enlightenment period brought positive change in how disabled individuals were treated, people suffering with mental retardation of any kind were still referred to by such names as *idiots* and other derogatory terms. “The term idiot was derived from the Greek; meaning the opposite of citizen, it denoted a person who did not take part in public life” (Winzer, 1993, p. 157). The word idiot was applied to anyone who seemed to have exceptionalities. However, during this time period of the nineteenth century the word also began to take on more of a medical and scientific meaning (Lewis, Strauss & Lehtinen, 1960). It was not until later in the 20th century that classifications for mental retardation were discovered and more changes occurred. The name idiot, in 2015, is something that educators could never imagine using as an identifying marker for individuals with disabilities. The philosophy that individuals with disabilities could be educated was advanced by Seguin (1866) during the mid-nineteenth century. Seguin’s contribution for this time period concerned the views regarding a disabled individuals’ educational capacity. Seguin documented that the disabled could learn through their senses.

Due, in part to Seguin (1866) and Itard’s (1932) work, society began to exhibit a desire to change and help individuals with disabilities. Seguin, also in 1848, was urged by Dr. Samuel Gridley Howe, a well-known physician, to travel to the United States to help educate people about individuals with disabilities (Howe, 1874). Howe’s work provided evidence that physicians and clergyman joined together during the 19th century

to promote an improved life for the disabled. This life included care and training necessary to maximize a disabled person's quality of life. Dr. Hervey B. Wilbur (1852) also joined Howe, in his journey to develop institutions for the disabled, where they could gain instruction and knowledge from professionals (Kauffman & Hallahan, 1981). Dorthea Dix (1843) also was an advocate for acquiring educational or instructional institutions for the disabled. This work identified her as one of the more prominent advocates for the disabled during this time period. Her appeal in 1843 asked legislators for funding to develop more prominent institutions for the disabled. In the appeal to the legislators, Dix stated, "I refer to idiots and insane persons, dwelling in circumstances not only adverse to their own physical and moral improvement, but productive of extreme disadvantages to all other persons brought into association with them" (p. 489). Dix also stated,

I come to present the strong claims of suffering humanity. I come to place before the Legislature of Massachusetts the condition of the miserable, the desolate, the outcast. I come as the advocate of helpless, forgotten, insane, and idiotic men and women; of beings sunk to a condition from which the most unconcerned would start with real horror; of beings wretched in our prisons, and more wretched in our almshouses. And I cannot suppose it needful to employ earnest persuasion, or stubborn argument, in order to arrest and fix attention upon a subject only the more strongly pressing in its claims because it is revolting and disgusting in its details. (p. 489)

Dix's plea helped try to reform the surroundings for people who were deemed insane, in order to give people with disabilities an education (Winzer, 1993). These changes to the given institutions were to help make them more facilities for education instead of holding facilities for the mentally ill.

Though the 19th century did not lead to an overall improvement of how the disabled were treated and educated, it did however, lay a foundation for future endeavors regarding special education (Kauffman & Hallahan, 1981). Unfortunately, with each triumph some setbacks were experienced, and in the latter part of the 19th century, the vision for how services would be provided to disabled people began to dwindle. Because there were some improvements in the uses of these institutions, an increase in the population who utilized the institutions kept rising, and the decrease of care because of this increased population began to become a problem (Kauffman & Hallahan, 1981). Along with this increase of people using the institutions in the United States after the American Civil War, also came an influx of immigrants whose societal characteristics were different from American society. Though such events as the National Education Association adding a Department of Special Education in 1887 occurred, and special training of the handicapped became more acceptable, there was still a downturn in services for the disabled who were still referred to as idiots and lunatics (Kerlin, 1875). Over time, the realization among society that the disabled were not only here to stay, but the likelihood of an increase in their existence over time, was very possible (Chaves, 1977).

Background of Special Education in the 20th Century

As the 20th century began, there were still feelings of discord toward the disabled. The theory of eugenics gained in popularity during this time. Eugenics, which was based on the belief that Social Darwinism or natural selection, is a process which assists with the elimination of the unfit, and therefore the process helps nature ensure that human

beings were healthy and normal (Guttek, 1986). The popularity of eugenics was even publicized in newspaper articles of the early 20th century. According to Barrett and Kurzman (2004),

Eugenics was an important scientific phenomenon in the first half of the twentieth century. Its proponents argued that humans, like other valued species, ought to reproduce according to scientific principles to generate the best possible genetic pool. Eugenacists (also called eugenists) urged states to adopt policies encouraging the reproduction of the “fit” and discouraging the reproduction of the “unfit”. (p. 497)

Galton (1883), a eugenics founder stated that eugenics was “Improving human stock by giving the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable” (pp. 24-25). Early eugenics practices were mostly concerned with intelligence of the individual, and were often related to social class (Barret & Kurzman, 2004). Such ideas as sterilization of the disabled were discussed, and legislation was passed to try and stop disabled people from reproducing and spreading disabilities among the healthy population (Kauffman & Hallahan, 1981). Though this was the way of thinking at that time, institutions for the handicapped were changing from facilities that housed the mentally disabled, which received funding from charities, to schools that educated the disabled. These facilities were still segregated, but with purely educational intentions opposed to past practice of housing them for mental issues (Turner, 1944).

One influence on this change was the legislation passed in 1852 called the *Compulsory Attendance Act*. Compulsory attendance regulations mandated that children must attend school by a certain age (Tropea, 1987). In the 20th century, the *Compulsory Attendance Act* began to be recognized as a regulation that should also include children with disabilities. This inclusion again helped facilitate change in educational institutions.

Before this enactment, people believed that the disabled had to be held in an institution with some sort of instruction. However, as time passed and the *Compulsory Attendance Act* was taken into consideration for children with disabilities, the disabled had to be placed in schools, which were deemed educational facilities (Tropea, 1987). Educators of this time did not want to deal with the burdens of disabled students, so segregated classrooms were utilized because they allowed the normal children to be educated without the disturbance from the disabled children, while also complying with the legislation for compulsory attendance. By 1911, there were over 100 American large city schools systems, which had developed special schools and special classes for children with disabilities (Callahan, 1962). By the 1920's educational facilities for the handicapped had increased to the point where two-thirds of the large cities in the United States had developed some sort of handicapped servicing for their surrounding area (Winzer, 1993, p. 315).

From 1910 to 1930, the variety of special classes for students with disabilities as well as the number of schools with special programming had increased (Goddard, 1912). This expansion in the middle to late 20th century helped to increase teacher training of the disabled, and more teachers were becoming trained in the areas of special education (Baker, 1944).

Background of Autism Spectrum Disorder in the 20th Century

From the early 1900's, ASD has been confused, and combined with a range of psychological conditions. This combining of ASD with a range of psychological conditions has led to confusion regarding identification and treatment of the condition

(Baker, 1944). The word autism comes from the Greek word *autos*, meaning self (Baker). The term *autos* described conditions in which a person is removed from social interaction hence, an isolated self (Yell, Drasgow & Lowrey, 2005).

In 1906, a man named Eugene Bleuler began using the word autism to refer to people who had similar characteristics as those with dementia (Ritvo, 1976). Bleuler later relabeled the descriptor for dementia as schizophrenia. He then used autism as more of a descriptor for those with mental disabilities who also had the defining characteristic of seeing the world in a selfish and self-centered manner (Ritvo, 1976).

In the 1940s, researchers in the United States began to use the term autism to describe children with emotional or social problems (Winzer, 1993). This usage of the term autism for diagnosis was led by two great pioneers for ASD, Leo Kanner and Hans Asperger. These two men are most well-known for their work with ASD, and their mission to prove that ASD was different from other emotional and mental disabilities (Feinstein, 2010).

Dr. Leo Kanner was born in 1894 in Klekotow, Austria and became an American psychiatrist, very well-known for his work with ASD. In 1930, he began to earn his reputation when he was selected to work at Johns Hopkins Hospital to develop the first child psychiatry service in a pediatrics unit (Bender, 1982). He then went on to become Associate Professor of Psychiatry in 1933. Kanner created the work that became the foundation for the study of autism when he wrote the 1943 document entitled, *Autistic Disturbances of Affective Contact* (Schopler, Chess, & Eisenberg, 1981). Kanner (1943) discussed the family background of eleven young children with severely disordered

behavior. Furthermore Kanner refers to five diagnostic criteria when discussing the children. According to Feinstein (2010), some of the criteria Kanner suggested can be described as follows:

profound lack of affective contact with other people; an anxiously obsessive desire for the perseveration of sameness in the child's routines and environment; a fascination with objects, which are handled with skill in fine motor movements; mutism or a kind of language that does not seem intended for interpersonal communication; good cognitive potential shown in feats of memory or skills on performance tests. (p. 24)

His document also referenced how parents care for their child and the genetic background may possibly have had some sort of responsibility for these children's' affect to others (Feinstein, 2010). This document also led to his development of the label of early infantile autism, and so this term began to be used by many researchers thereafter.

Kanner's (1943) document also examined the parents' role in their children's ASD diagnosis. He suggested how he thought the children of his study had great potential cognitively, but their parents were responsible for their social inadequacies. Kanner suggested that autism may be related to a genuine lack of maternal warmth. Kanner states, "In the whole group, there are very few warmhearted fathers and mothers." (p. 250). This was a similar view shared by another psychological specialist of this time. During the latter 1950's and early 1960's a professor of psychology named Bruno Bettelheim, had a similar theory as his research created the theory of the *refrigerator mother*. The refrigerator mother was said to be a theory of the origin of autism faulting the mother and the lack of the maternal bond (Daniels et al., 2008). For several years, the refrigerator mother theory was widely accepted by the medical field and little research was conducted to debunk this view. Kanner's views differed in some respects from

Bettelheim's, but in other respects he shared similarities with Bettelheim as well. An example of the similarity was when Kanner was interviewed in 1960 by *Time Magazine*. He told the interviewer, that the children he studied were born from "parents cold and rational who just happened to defrost long enough to have a child" (p. 80).

Discussing a parent's role in their child having ASD was very controversial at this time because of the eugenics movement and peoples' feelings toward weeding out the feeble based on parental genetics (Folstein & Rutter 1977). However, this debate continued for several years. During this time period, children continued to be psychoanalyzed individually and with their mothers to try and identify whether or not detachment from the mother child bond was responsible for autistic like characteristics (Kauffman & Hallahan, 1981). After further research was completed during the 1960's, analysts found that there was more to the diagnosis than had been discussed in prior research. Findings of cognitive deficits in the areas of disturbances of perceptions, disturbances of developmental rate, disturbances of relating, disturbances of speech and language and disturbances of motility, which began to disprove the detachment theory (Kauffman & Hallahan, 1981). Research completed by Rimland (1964), further disproved the refrigerator mother theory, and began the journey for clearer research.

Dr. Hans Asperger was born in 1906 in Austria, and throughout his career, he became a pediatrician, medical theorist, and medical professor (Lyons & Fitzgerald, 2007). Asperger (as cited in Feinstein, 2010) published a definition of autistic psychopathy entitled, *The 'Autistic Psychopathy' in Childhood*, in 1944. Similar to Kanner's (1943) work, Asperger's document studied small children. Asperger noticed

that many of the children he identified as being autistic used their special talents in adulthood and had successful careers (Attwood, 1997). After the publication of his landmark paper describing autistic symptoms, Asperger was declared a very reliable source for research regarding ASD (Echo, 2007). There has been much controversy regarding Kanner's and Asperger's works. Researchers often wonder which came first. Some say Kanner used Asperger's works prior to them being published for information for his 1943 document, but no proof of this has been actualized. Similar to how Kanner's views were analyzed under a microscope of questioning regarding allusions to eugenics, so were Asperger's views (Echo, 2007). Asperger went on to accomplish many goals such as becoming director of a children's clinic as well as being appointed chair of pediatrics at the University of Vienna. In 1981, Lorna Wing another well-known psychiatrist coined the term Asperger's Syndrome as yet another distinction in the umbrella of autism. This diagnosis was named Asperger's syndrome in honor of Hans Asperger and all of the work he completed for the betterment of the understanding of ASD (Wing, 1981).

There was also research to be completed to address the need for differentiation between autism and schizophrenia. There was hope that the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) was developed to assist in that differentiation, however this was not the case. In 1952, the first edition of the DSM was published, and it stated that schizophrenia was a disorder caused by autism (American Psychiatric Association, 1952). Well into the 1960s, autism and schizophrenia continued to be linked in research; however, many researchers knew that there was much

more about autism that had not been revealed (Winzer, 1993). Therefore, medical professionals began to research a reason for separating the two diagnoses. Even the next issue of the DSM, the DSM-II did not make this clarification. However, the debate of autism vs. schizophrenia was clarified once the 1980 publication of the DSM-III was published. The authors stated that autism was found to be different from schizophrenia and given its own category with Pervasive Developmental Disorder (PDD) (American Psychiatric Association, 1980).

As the 1950's and 1960's passed, there was also a brighter outlook on what people with disabilities could accomplish. The Civil Rights Movement brought a number of parent advocacy organizations to the surface, which led to even more awareness in the area of ASD and education (Martin, Martin & Terman, 1996). There was a change in momentum for parents of children with disabilities. Parents began to advocate for their children's rights in the school system. Society not only saw a purpose for what people with disabilities should be taught, but how those teachings would affect them if they were given the opportunity to utilize what they learned in school when entering society. Society began to realize that handicapped students deserve as many rights as regular citizens (Winzer, 1993). Therefore, schools became more standard with classes offered for mentally retarded children, and this in turn gave parents more reassurance that no matter what school their child attended, the programming would be the same in any city or state in which their child lived (Baker, 1944).

The legal system also helped the progress in education for individuals with ASD and their instructional needs. One of the most well-known court cases of our time, *Brown*

v. State Board of Education, shaped regular education procedures while in turn helping special education for the future. *Brown v. State Board of Education* in 1954 declared that racially segregated education is inherently unequal. “In effect, *Brown* invalidated the former 'separate but equal' doctrine, reasoning that racial segregation denies the constitutional right of equality of education” (Davis, 1986, p. 291). According to *Brown v. State Board of Education*, specific wording used in the case argument states,

Segregation of white and Negro children in the public schools of a State solely on the basis of race, pursuant to state laws permitting or requiring such segregation, denies to Negro children the equal protection of the laws guaranteed by the Fourteenth Amendment - even though the physical facilities and other “tangible” factors of white and Negro schools may be equal. (pp. 486-496)

Because the Brown case dealt with discrimination and education, it has been a constant reference for discrimination cases in special education for children with disabilities (Davis, 1986).

With the dramatic change from the Brown case, the 1960's brought with it more opportunities for disabled individuals. These opportunities came as a result of the increased improvements in funding and programming. Schools established programming for children with disabilities at the state and local levels (Martin et al., 1996). Education began to assume some responsibility for seriously emotionally disturbed students and this encompassed those students deemed autistic.

Over time, the therapeutic approach for children with autism changed drastically (Yell, Drasgow, & Lowrey, 2005). Treatments for autism included: drug induced, pain induced, and behavior regulated treatments (Lyons & Fitzgerald, 2007). Due to the need for a more humane treatment and education for these students, the 1980's and 1990's

brought into practice behavior therapy and controlled learning environments that emerged as the primary treatments for many forms of ASD and related conditions (Yell et al., 2005). These treatments helped individuals with ASD become more socially acceptable by helping to deter individuals from self-injurious behaviors, improve their speech and begin to learn to care for themselves (Ritvo, 1976). This improvement was again in part due to the Civil Rights movement, but also because of President Kennedy's leadership in office.

President Kennedy had a disabled sister named Rosemary, so his experience helped to shed light on many significant issues regarding people with disabilities (Feinstein, 2010). Eunice Kennedy Shriver, President Kennedy's sister also played a very important role in his changes in legislation because of her connection to her Rosemary as well. Eunice was responsible for starting the Special Olympics, which was an organized athletic event that allowed people with disabilities to compete and earn awards (The Special Olympics, 2012). Due to these influences and his family's drive to ensure people like Rosemary had a voice, President Kennedy was responsible for sending panels of people overseas to do research for programming for the handicapped to ensure that the best programs were brought to the United States.

In January, according to the report from the United States Department of Labor, Children's Bureau (1940), "Schools should give increased attention to the educational needs of individual children, including those who are physically handicapped, mentally retarded or socially handicapped" (p. 183). This increased attention improved the amount of funding designated for special education in the schools involving programming

(United States Department of Labor, 1940). “In October 1963, President Kennedy signed Public Law 88-164, which broadened the earlier legislation (Education of Mentally Retarded Children Act-Public Law 85-926) to include most children with severe handicaps” (Martin, 1968, p. 378). Public Law 88-164 or the Mental Retardation Facilities Construction Act increased the coverage of the legislation and mandates regarding care and the facilities for people with disabilities, which broadened to include disabilities such as “hard of hearing, deaf, speech impaired, visually impaired visually handicapped, seriously emotionally disturbed, crippled, or health impaired children who by reason thereof require special education” (Burke, as cited in Winzer, 1993, p. 144). Amendments to these public laws soon followed to include other items which were not included prior, and these items eventually helped individuals with ASD based on their specific deficits.

The 1970's brought with them the questioning of segregation and if it was the best idea for the education of disabled students (Davis, 1986). Advocacy groups began to form and society began to question whether or not disabled students are different from the norm (Martin et al., 1996). They also began to question to what degree the disabled are different, and what does this mean to educate them. With the increase in advocacy groups, special education in the United States took on a new definition with the introduction of the Congressional approval of the Education for All Handicapped Children Act also known as Public Law 94-142 (Martin et al., 1996). Though this law actually became recognized in 1975, it was not until the early 1980's that school leaders began to change their practices to begin to recognize the educational rights of students

with disabilities (Mandlawitz, 2002) According to Public Law 94-142, localities were to support individuals with disabilities by following several guidelines to the mandates placed on educational facilities. An example of a portion of the mandate states,

(B) that (i) handicapped children in private schools and facilities will be provided special education and related services (in conformance with an individualized educational program as required by this part) at no cost to their parents or guardian, if such children are placed in or referred to such schools or facilities by the State or appropriate local educational agency as the means of carrying out the requirements of this part or any other applicable law requiring the provision of special education and related services to all handicapped children within such State, and (ii) in all such instances the State educational agency shall determine whether such schools and facilities meet standards that apply to State and local educational agencies and that children so served have all the rights they would have if served by such agencies. (Education for all Handicapped Children Act, 1975, p. 89)

Throughout the history of public schools in United States, services to children with disabilities were minimal and were often administered at the discretion of the school districts (Martin et al., 1996). Often times, students with disabilities were allowed regular education without any special services, or they were given special services and at times those services were often insufficient (Martin et al., 1996).

After Public Law 94-142 took full effect in 1978, education for all became a topic for discussion among schools (Ballard & Zettel, 1978). PL 94-142 required public schools to provide free appropriate public education to students with a wide range of disabilities, including “physical handicaps, mental retardation, speech, vision and language problems, emotional and behavioral problems, and other learning disorders” (Martin et al., 1996, p. 30). PL 94-142 also mandated that school districts provide such schooling in the least restrictive environment possible (Ballard & Zettel, 1978).

Another prominent legal case in history which helped clarify the terms of PL 94-142, was the court trial in 1982 between the *Board of Education of the Hendrick Hudson Central School District, of Westchester County v. Rowley et al. Rowley*. The U.S. Supreme Court ruled that Amy Rowley, a young woman who was a deaf student in a New York public school, was receiving the proper services within the school day to be considered a free and appropriate public education (Davis, 1986). Amy and her parents requested that she receive a sign language interpreter for all of her classes and by denying her this interpreter it would be denying her rights as stated in Public Law 94-142 (*Board of Education v. Rowley*, 1982). However, the Supreme Court stuck by its decision that the school did not have to provide the interpreter for Amy in all of her academic classes. The term appropriate in the part of the document that read free and appropriate education was not defined, and Amy was successful with the services she was currently being provided. This, in the courts opinion meant she was successful in the academic environment (Aldersley, 2002). These important historical events have left permanent marks on how special education is interpreted today. These events also affect how students with ASD are viewed. The Rowley case became one of the most prominent cases in history for special education because it developed what is now known as the Rowley Standard. The Rowley Standard has helped schools understand what their legal responsibilities are to students with disabilities. The court case has not only helped protect schools, but it has also helped protect students with disabilities (Davis, 1986). The Rowley Standard has helped schools regulate services to students with disabilities, so they are able to demonstrate educational benefit and progress (Gordon, Kasper, Israel &

Fine, 2005). Once this progress and benefit has been demonstrated, a school is no longer under obligation to provide additional services or every possible related service in order to maximize the student's potential (Davis, 1986).

During the 1980's and through the 1990's, the diagnosis of autism changed and broadened to Autism Spectrum Disorder (ASD). In 1990, PL 94-142 was renamed the Individuals with Disabilities Education Act (*Individuals with Disabilities Education Reauthorization Act*, 2004), and since then there have continued to be reauthorizations and improvements made on behalf of children with disabilities (Martin et al., 1996). From this change in diagnostic criteria and regulation, students with ASD were found to require more specialized accommodations (Yell et al., 2005). These specialized accommodations may have been due to the change in categorization in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), the reference book used by health-care professionals to diagnose mental health disorders (Bowen-Dahl, 2003). The change in categorization changed the diagnosis of autism from being related under the category of schizophrenia to a developmental disorder separate from schizophrenia (Mandlawitz, 2002). The change in categorization affected the way schools treated students with ASD, because it allowed student with ASD to be differentiated from having mental retardation, and instead allowed students with autism to be viewed as educable (Winzer, 1993). With this new diagnostic clarification in the DSM, researchers found that the main symptom specific to ASD is lack of social interaction and communication (Boyd & Shaw, 1987). In fact, some children with ASD are nonverbal and/or have difficulty interpreting body language or holding a conversation with others (Mandlawitz, 2002). There are still

several subcategories under the umbrella of ASD. Some of these categories share similar characteristics, but are only used as a guideline because no two students are exactly the same, even though they may share the same diagnosis.

CHAPTER III
PIONEERS AND ADVOCATES FOR THE MEDICAL FIELD FOR
AUTISM SPECTRUM DISORDER

Chapter Description

Chapter III will discuss medical developments regarding ASD from 1980-2013 plus the pioneers and advocates who influenced these developments. This chapter will include such discussions as an overview of the lives and accomplishments of the two most renowned pioneers of all time in field of ASD, Leo Kanner and Hans Asperger. Chapter III will also include information regarding the work of Lorna Wing and a discussion of how she was influenced during her time spent with Hans Asperger. The chapter will continue with a discussion concerning the evolutionary influences of Margaret Bauman and her findings regarding the neurological components relating to the diagnosis of ASD. In addition to the findings of these major pioneers and advocates, discussions regarding the changes in the DSM from the third edition to the proposed changes for the fifth edition will also be highlighted.

The changes and influences of the DSM include such details as revisions in terminology and diagnostic criteria of ASD, changes in the definition of PDD, PDD-NOS, and the inclusion of the Asperger's Syndrome diagnosis plus the more current possible exclusion of the diagnosis from the DSM. These changes will be discussed to demonstrate the influences that these classifications of diagnosis have had on the identification of individuals with ASD and the related statistics.

Chapter III will also discuss some of the discoveries in the research which determined the cause and/or neurological and biological markers thought to be critical in the identification of ASD from 1980 to 2013. These discoveries in research will then be discussed to reflect the influences the research has had on the evolution of ASD research. Such research discoveries will include the possible influence of the maternal and paternal age on the fetus, neurological markers on the fetus, a possible genetic or familial link to causation, and the possible prenatal signs and risk factors. Chapter III will also include the controversial discussions concerning the role vaccinations have played in the diagnosis of ASD. This discussion will include the study completed by Andrew Wakefield in 1998 regarding the use of Thimerosal in the MMR vaccine, and how in 2002 his study was discredited.

All of these changes and influences in the medical field relating to ASD will demonstrate how the medical field has played a role in the evolution of ASD and how the great pioneers and advocates, have had a hand in being catalysts for influence and change whether their influences were positive or negative in nature.

Pioneers/Medical Field

Leo Kanner

Dr. Leo Kanner was very well-known for his work with ASD. Kanner (1943) discussed the family background of 11 young children with severely disordered behavior. In his work, Kanner defined much of what we refer to today as autism. Due to the great work done in his paper, ASD is now viewed that is a disorder that is completely separate from psychiatric disorders, when it was once deemed very closely related to

schizophrenia. Kanner stated, “But inspite of remarkable similarities, the condition differs in many respects from all other known instances of childhood schizophrenia.” (p. 248). Some researchers today disagree that Kanner was responsible for these gains because he was unclear as to how the differentiation was to be declared, however it is important to once again note that Kanner developed five diagnostic criteria. This development was part of his contribution to the medical field and ultimately affected how ASD was viewed medically. Because of these medical discoveries, currently, schools, the public and medical professionals not only differentiate between ASD from other disorders, but they also treat people with ASD according to a version of Kanner’s diagnostic criteria. People who diagnose ASD are now able to use these criteria to assist them in their judgment during the diagnostic process. The criteria are as follows:

profound lack of affective contact with other people; an anxiously obsessive desire for the perseveration of sameness in the child’s routines and environment; a fascination with objects, which are handled with skill in fine motor movements; mutism or a kind of language that does not seem intended for interpersonal communication; good cognitive potential shown in feats of memory or skills on performance tests. (Feinstein, 2010, p. 24)

Kanner (1943) also referenced prior studies that referred to how parents played a role in child development. One of the terms that Kanner’s work is most known for is his defining of the terminology early infantile autism, which was then used in many studies that came after his. This terminology, once again demonstrated that Kanner made strong gains in separating ASD from the stigma it gained being deemed a disorder of people who are institutionalized. His work also made people aware that at a young age, this diagnosis could not only be identified, but with close observation and treatment, it could be treated for improvement.

Kanner's (1943) examination of the parents' role in their child's ASD diagnosis was extensive. His suggestions indicated that he thought the children of his study had great potential cognitively, but that their parents were responsible for their social inadequacies. His position on this issue drew quite a large speculation that Kanner believed parents were responsible for causing ASD. One of the statements that led to this belief was when Kanner made mention that "For the most part the parents, grandparents and collaterals are persons strongly preoccupied with abstractions of a scientific, literary or artistic nature and limited in genuine interest in people" (p. 250). Kanner had these views because of his report where he suggested that autism may be related to a genuine lack of maternal warmth.

There was much controversy then, as there has been years after, that Kanner believed this to be truth, and therefore Kanner received significant backlash from the parents of children with ASD that he treated (Feinstein, 2010). Kanner (1941) religiously stated at conferences and in interviews that this was not the case and that he believed it was more innate than about parental involvement. However, Kanner suggested that this confusion occurred because of his beliefs that once diagnosed with ASD, a child needed to have treatment that facilitated bonding between the child and parent, and that if parents, due to the trauma of diagnosis, did not respond to this need there began a greater decline in that social bond children needed for normal social development (Kanner, 1949). Because Kanner desired a clearer delineation between ASD and a more psychiatric diagnosis this seemed to drive his insistence that he believed that ASD was not developed due to lack of parental contact, but was present from birth.

Kanner (1973) gained more ability to differentiate between the two different disorders and stated “emotional deprivation has profound consequences for psychobiological development” (p. 28). However, due to this confusion of what Kanner really meant, the debate about who was to blame for causing ASD continued for several years. After further research was completed during the 1960's, analysts found that there was more to the diagnosis than had been discussed in prior research. Findings of cognitive deficits in the areas of disturbances of perceptions, disturbances of developmental rate, disturbances of relating, disturbances of speech and language and disturbances of motility, began to disprove the detachment theory (Kauffman & Hallahan, 1981). Rimland (1964) further disproved the refrigerator mother theory, and began the journey to provide more definitive research.

All in all, Kanner (1943, 1949) has paved the way for people with ASD to receive the best care by identifying the key components of the disorder as well as separating it from other disorders, so that it can receive proper care according to the direct needs people with ASD have. Without this work, ASD may have never been declared separate from other cognitive or developmental disorders. Whether or not people believed that Kanner was the first to uncover these realizations or not his direct attention toward ASD cannot be denied.

Hans Asperger

Dr. Hans Asperger was clearly known for the work that he produced to delineate the identifying behaviors in children, so that a diagnosis for ASD could be realized at a

much earlier age and could be recognized when compared with other disorders. Because of Asperger, patterns of behavior and abilities that included

a lack of empathy, naïve, inappropriate, one-sided interaction, little ability to no ability to form friendships, pedantic and repetitive speech, poor nonverbal communication, intense absorption in certain subjects, and clumsy and ill coordinated movements and odd postures were looked at to be key components in the diagnosis of ASD with a special focus on what is now called Asperger's syndrome. (Burgoine & Wing, 1983, p. 261)

During his research, Asperger noticed that many of the children he identified as being autistic used their special talents in adulthood and had successful careers (Attwood, 1997). However, with that being said, Asperger also discussed the children's deficit areas by saying,

It will be clear by now that the personality of the children presented lacks, above all, harmony between affect and intellect. While intellect may often be above average, drives and instincts are often severely disturbed. This is shown in the failure of instinctive situational adaptation and when faced with the practical demands of ordinary life. (Asperger as cited in Frith, 1991, p. 178)

Deficits such as issues with eye gaze, gestures, postures, humor and prosody were more of his focus where Kanner (1991) discussed more issues with verbal communication in his study (Frith, 1991). These findings again definitely paved the way for people with ASD to be given respect because of their identified skills as well as differentiated their identifying markers during diagnosis. Frith stated that "Asperger's pioneering paper published in 1944 is part of the classic literature of child psychiatry, and a landmark in the development of the concept of autism" (p. 39). After the publication of his landmark paper describing autistic symptoms, Asperger was declared a very reliable source for research regarding ASD (Wing, 1981).

There remains today active controversy about which pioneer is truly responsible for the first works toward ASD. The important thing to remember is that because of each of these two pioneers, and their contributions, ASD became known as a disorder that was more than just a mental disability, and people with ASD were given the start of a voice that has now been heard (Feinstein, 2010).

Lorna Wing

Lorna Wing was an English psychiatrist and physician who had a daughter with identified autism. Her personal battle with her daughter's diagnosis and the life that she lived motivated her to find more answers regarding the diagnosis, cause and treatment of ASD. The medical developments that Wing is responsible for widely revolved around her works with Hans Asperger (Gillberg & Gillberg, 1989). From the work with Asperger, she was able to develop her framework for future research.

After speaking with Hans Asperger about her research regarding ASD, Lorna Wing took his research, after he died in 1981, and combined it with her own into an educational document entitled *Asperger's syndrome: a clinical account* regarding the criteria and understanding of the diagnosis of ASD (Feinstein, 2010). Because this document was recognized as the first time the term Asperger's Syndrome was ever used, this was a remarkable change for the medical world because it then forced the medical field to acknowledge Asperger's Syndrome as part of the spectrum of characteristics under the umbrella of autism (Frith, 1991). Wing worked to combine and clarify the work of Kanner and Asperger. In doing so, she also preserved the findings and added to

the research. She was able to define and differentiate the key similarities and differences between their works as highlighted in Table 1 below (Wing, 1981).

Table 1

Similarities and Differences between Kanner's and Asperger's Work

Similarities	Differences
<ul style="list-style-type: none"> -Marked excess of males over females -Social isolation, egocentricity and lack of interest in the feelings or ideas of others -Language usage -Impaired non verbals communication such as eye contact, lack of expressive gestures, and unusual vocal intonation -lack of imaginable play -repetitive patterns of activity and fixations -Difficulty with sensory stimuli -Gross motor deficits -Behavior problems, aggression and restlessness -Good rote memory 	<ul style="list-style-type: none"> -Asperger's subjects developed speech before school age Kanner's did not -Asperger mentioned that his subjects could often be described as odd in appearance where Kanner stated many times that his subjects had an attractive look as he called them -Aspeger thought his subjects had originality of thought even if it was often of little practical use -Asperger unlike Kanner did not compile a list of diagnostic criteria for his syndrome. His features were taken from the descriptions of his discussions of cases

Source: Wing, 1981.

In her work with Asperger, Wing is also well-known for her contribution to the medical field by declaring that ASD was a spectrum disorder with many levels and distinctions, but also similarities. She developed her research into some of the most widely necessary and consistently utilized research by the medical field of today (Feinstein, 2010). Evidence of Wing's beginning recognition of the spectrum can be found in her discussion of the *triad* of shared deficits that an ASD diagnosis demonstrated (Wing, 1989). In describing the triad of impairments, Wing stated, "impairment of social interaction was virtually always accompanied by impairments of

social communication and of imaginative development, especially in social aspects” (p.

9). When Wing declared ASD as a spectrum disorder, it opened minds in the medical field and caused them to take into consideration that the range of characteristics from a person who is suspected to have ASD can vary drastically hence the spectrum belief (Feinstein, 2010). Wing was also known for her thoughts that ASD was a disorder where some of the characteristics were shared by the average person. This made her work even more important when distinguishing characteristics for diagnosis. Wing (1981) stated that

A number of normal adults have outstandingly good rote memories and even retain eidetic imagery into adult life. Pedantic speech and a tendency to take things literally can also be found in normal people. It is possible that some people could be classified as suffering from Asperger's syndrome because they are at the extreme end of the normal continuum on all these features. (p. 120)

By stating this in her research she gave the medical field and those affected by ASD a voice. Declaring some of the characteristics of ASD as *normal* caught the attention of many and made the disorder more human and relatable (Echo, 2007). This relatable discovery allowed ASD to gain more attention to the need for better diagnostic tools to differentiate between the characteristics as well as better treatments to help foster their skills and help them to become more independent (Echo, 2007).

Wing's many accomplishments ranged from enhancing the diagnostic process to discovering new and improved ways to add to treatments and minimize the stress on parents trying to seek answers for their children (Feinstein, 2010). Wing wanted to minimize the feelings of insecurity and lack of knowledge she saw in parents regarding what their next step should be to obtain the best care for their children at the youngest possible age. She also sought to enable parents to increase their knowledge base. Wing,

now deceased, is widely revered for her work that is now looked at as a basis by which ASD is measured on a spectrum of differences and similarities.

Margaret Bauman

Margaret Bauman is the next pioneer who will be discussed in this chapter because she is responsible for many of the advancements regarding the neurologic markers of ASD and how discovering these markers has increased ASD research. Margaret is a well-known, pediatric neurologist who is best known for being the first person to distinguish the differences between a typical brain and a brain with ASD (Feinstein, 2010). These findings have helped ASD declare a neurological component to its diagnosis and set aside the belief that there were more behavioral causes for the disorder. Bauman's (1991) research helped deny the idea that ASD was caused by negligence in parenting or lack of bonding with the mother, also known as the *refrigerator mother* phenomena. The research indicated that people with ASD had a medically based neurological issue, which would call for interventions to be created and not simply look for a change in parenting techniques (Bauman, 1991).

Bauman (1996) stated in her research that "with heightened clinical interest in the disorder, coincident with advances in medical technology, evidence for an underlying neurologic basis for autism has become increasingly apparent" (p. 791). Bauman used this knowledge to influence research by developing several research experiments that focused on what these neurological markers mean for the diagnosis with hope that eventually the causation will be discovered. Bauman's research has gone from the identification of some of the first neurological differences in a typical brain compared to

a brain with ASD to the founding of her Learning and Developmental Disabilities Evaluation and Rehabilitation Services (LADDERS) program. The LADDERS program was first developed and operated through the Youville Hospital in Cambridge, but now is housed out of Massachusetts General Hospital. The LADDERS program has now become an integral part of the services offered for patients with ASD at the Lurie Center for ASD at Massachusetts general hospital, in order to better serve parents who were looking for a place that had all services necessary for their child are offered (Massachusetts General Hospital, 2012).

Diagnostic and Statistical Manual from III-5

DSM is a guideline for mental disorders that gives a standard by which to compare disorders to one another, as well as offering criteria for each disorder by which everyone can determine a diagnosis. The DSM was created in 1951, and was published in 1952 as a means of having one common way to diagnose and one common definition of terms or verbiage that could be used by medical professionals (Houts, 2000). Throughout all of these changes to each addition to the DSM the definition of criteria for ASD has evolved and changed. During the 1980's to 2013 there were several changes that affected the medical field regarding the DSM and its classifications of ASD. The DSM-III was developed in the late 1970's and was published as the current issue in 1980 (American Psychiatric Association, 1980). It classified ASD as Infantile Autism, Residual Infantile Autism, Childhood Onset Pervasive Developmental Disorder (PDD), and Residual Onset PDD (American Psychiatric Association, 1980). From this classification, there was a significant recognition and clear distinction between a PDD

and other mental disorders. However, due to the need for a change in categories or description of categories, the DSM-III needed a revision, which is where the DSM-III-R was created (Volkmar, Bregman, Cohen, & Cicchetti, 1998).

DSM-III-R was published in 1987. This publication was actually a revised version of the DSM-III because there needed to be significant changes to the criteria or the specific categories for a given disorder so a revision had to take place (Volkmar et al., 1998). The difference in ASD for the DSM III and the DSM III-R is that the diagnostic criteria for ASD broadened, therefore leading to a more defined criteria and a larger parameter for diagnosis because the broadening of the criteria means a more all-encompassing definition of terms (American Psychiatric Association, 1980; American Psychiatric Association, 1987). The only draw-back to this broadening of criteria is over diagnosis can and did take place at times because of the wide variety of criteria that a person suspected of ASD had to meet (Cooper, Balsis, & Zimmerman, 2010).

The evidence for change was due to the need for more specific criteria to narrow the diagnosis and curtail the chance of over diagnosis since the rise in identification had increased so dramatically (Autism Speaks Inc., 2013). However, there has been no evidence that ASD has only risen in occurrence based solely on diagnosis and not a different identifying marker. Therefore, along with several other changes to disorders other than ASD, came the changes that required the ASD diagnosis to become more clearly defined. In 1994, the DSM-IV published changes in what is referred to as clinical significance criterion. These changes required that symptoms of the disorder that were being described have clinical significance. This meant that any issues a person was

having that were within the range of the speculated disorder needed to cause the person some sort of impairment in his life whether it be in the social realm, within a job or in other important areas which affect his life with some rate of significance (American Psychiatric Association, 1994). This would then allow the person to gain the diagnosis of that given disorder. Referencing ASD to this change from the DSM-III to the DSM-IV meant that ASD needed to follow these criteria as well. This changed the dynamics of the disorder especially because there was what was considered an umbrella of different diagnosis under the PDD label (Cooper et al., 2010).

The DSM-IV was changed to include five PDDs, Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (American Psychiatric Association, 1994). These definitions and specific categories that the symptoms and characteristics were placed in allowed for differentiated diagnosis, which helped in schools and medical facilities by creating more individualized treatments instead of one large treatment group as DSM-III tended to create. The delineation between these categories allowed for differences in verbal communication vs. non-verbal and also Intelligence Quotient (IQ) differences, which often had puzzled medical professionals and educators because these differences require a change in how people who fall into these different categories are treated and educated. This was a huge change for people with ASD and parents who believed that their child with Asperger's Disorder for example was not the same as a child diagnosed with Autistic Disorder. In 2000, there was

yet another revision in the DSM-IV-TR, however, only slight changes were made for ASD during this revision time.

The most current revision of the DSM is the DSM-5. This version was approved for publication on December 1, 2012, but was not published until May 18, 2013. The DSM-5 drew much publicity because the differentiation in diagnosis that was somewhat fought for in the DSM-IV was now going to be changed in a manner that could not only change diagnosis, but could also affect funding, insurance coverage, treatment plans, education and the way the ASD diagnosis was made (Maenner et al., 2014).

Another more social piece to the change in diagnoses was now that all of the disorders came truly under an umbrella, but not the umbrella of PDD, which at times was deemed more socially acceptable, but under the umbrella of ASD. Often, people would refer to all children on the spectrum as having autism, but parents and people with different categories of ASD placed parameters on the label because even though there were similarities to them, there were significant differences (Feinstein, 2010). Placing the official name of ASD in the DSM-5 made parents uneasy to think that their child would be labeled as having *autism* when they had a higher functioning extremely intelligent child who was a much more productive child and had been diagnosed with Asperger's Disorder (Maenner et al., 2014).

One of the most significant changes is that the separate labeling of Autistic Disorder, Asperger's Disorder, and PDD-NOS will no longer be the way of diagnosis. The new term that defines the ASD diagnosis is now the umbrella term that was the term used to define the wide span of characteristics between the PDDs and that is Autism

Spectrum Disorder (American Psychiatric Association, 2013). The differentiation between the areas will now be deciphered by severity level. The differentiation between the levels are based on the differing characteristics such as needs in communication support, support during everyday activity, socialization support, low variety of interests and practiced repetitive behaviors. The diagnosis would then look like Autism Spectrum Disorder, but the diagnosis would be given a Level #1, Level #2, or Level #3 to differentiate between the different levels and severity of the defining characteristics (American Psychiatric Association, 2013).

Medical professionals, educators, parents, ASD advocates as well as people with ASD wanted answers as to why such a drastic change was made. The American Psychiatric Association believed that the last diagnosis and separation of the categories was inaccurate causing a lack of uniformity in the diagnosis process between physicians (Giles, 2014). They also believed that since some of the behaviors shared some common traits that the name of the disorder should be the same, but the level of those commonalities should be different because that is where the need for support is determined.

One of the major issues with the DSM-5 changes was the removal of the Asperger's Disorder and PDD from the formal diagnosis. Not only is this a drastic change medically, but also emotionally for the people who are diagnosed with this disorder. There was also worry in the area of criteria because raising the amount of criteria needed for the diagnosis could possibly decrease the amount of people diagnosed because in order to receive the ASD diagnosis, one must have all of the attributed

characteristics in order to qualify. Another way that the criteria have changed is in the domains of qualification. In the DSM-IV, the domains were communication, social interaction, restricted interests and repetitive behaviors (American Psychiatric Association, 1994). In the DSM-5 for clarification within the domains, some domains have been combined for a more concise and clear picture. An example of this is the communication and social interaction domain, which is now combined into social/communication deficits (American Psychiatric Association, 2013). Another change is the elimination of the language delay requirement as one of the qualifying factors of the disorder. In the new edition, the Communication and Social Interaction domains will be combined into one entitled, *Social/Communication Deficits*. Additionally, the requirement of a delay in language development is no longer necessary for a diagnosis, which was a major change considering it was one of the first characteristics ever identified for ASD (Giles, 2014).

It remains to be seen how these changes will affect people with ASD over time. Extremely high functioning people with Asperger's disorder may not qualify any longer to receive services or special insurance coverage, which will affect the way they receive treatment, support and educational needs (Giles, 2014). The long term effects of the changes will not be understood for years to come, however this would be an area of further research in the future.

Andrew Wakefield and Vaccinations

Wakefield (1998) a medical researcher, as well as gastroenterologist, made claims that would change the face of ASD and the way society viewed then protection of

vaccinations for their children forever. Wakefield went public with his research that the Measles Mumps and Rubella vaccination also known as the MMR could have a direct link to the causation of ASD as well as different types of bowel issues (Wakefield et al., 1998). These findings came when he conducted a research study using children with ASD and bowel issues and noticed that all of them began to demonstrate symptoms of both disorders within days after receiving the MMR vaccine (Wakefield et al., 1998). This caused Wakefield et al. to make the claim that too many vaccines at such a young age meant that children were suffering and would continue to be diagnosed with issues directly caused by the MMR vaccine. Wakefield (as cited in Feinstein, 2010) further went on to explain that the vaccine itself, predominantly the measles vaccine, could be damaging to the intestine therefore causing brain damage. Wakefield et al. (1998) stated,

for 15 of 20 autistic children, the first symptoms developed within a week of vaccination. Gupta commented on the striking association between measles, mumps, and rubella vaccination and the onset of behavioural symptoms in all the children that he had investigated for regressive autism. (p. 639)

Therefore, implying that until further research was completed; parents should wait to have their children inoculated with the MMR vaccine.

As Wakefield's findings began to create public chaos over vaccinations, the public began to question all vaccinations and what chemicals were used to create them (Feinstein, 2010). Researchers began to analyze the additives in vaccines and Thimerosal, which is a binding agent added to vaccine. Through all of the pandemonium, there was negative press caused by anti-vaccination campaigns and chaos regarding not having children vaccinated and what that meant for the health of the public (Vijendra & Jensen, 2002). The fear was that the lack of vaccinations received over time

would begin to cause diseases that had been eradicated, to resurface. Wakefield was the cause for all of this controversy, and this sparked several other researchers to come forth with their own research. Some found that the MMR vaccine had no adverse effects and others came with resounding evidence that Wakefield's research was absolutely true (Vijendra & Jensen, 2002).

Wakefield's credibility was significantly questioned in 2004, as his coauthors were beginning to denounce their involvement in his study. Finally in 2010, the *Lancet*, the British medical journal that published his article in 1998, rejected his article, and Wakefield was identified as having fabricated most of the information in the study (Harris, 2010). From this backlash came many derogatory reports from magazines and newspapers alike (Dominus, 2011). However, even though these reports were extensive and discussed Wakefield's fraudulent claims, Wakefield stood by the findings in his study that vaccinations played a role in ASD (Dominus, 2011). These derogatory reports as a whole discredited Wakefield's research, but to his staunch supporters, some to this day, still believe that the MMR vaccine has an effect on the causation of ASD.

Today, the public is still somewhat split when it concerns vaccines. Some feel completely relieved that the research demonstrates no residual effect from the MMR vaccine, but there are and probably always will be the people who believe what Wakefield et al. (1998) stated. Andrew Wakefield will forever have changed ASD and how we as the public view the health and safety of children (Houts, 2000). It has also changed the pediatricians administering the vaccines because they are now being questioned as to their beliefs and what they recommend. Because of these events, it

would be considered common for parents to entertain doing one of three things regarding vaccinations. They either vaccinate their children based on the recommended vaccination schedule from the American Academy of Pediatrics or they have their child on a delayed vaccination schedule which is recommended by some very well-known doctors, one in particular is Dr. Robert Sears a well-known and trusted pediatric doctor, or some parents choose to only give some vaccines or to not vaccinate at all (Sears, 2007). Whatever each parent chooses and whether or not Andrew Wakefield's supposed findings affected those decisions, he needs to be viewed as a pioneer for ASD. This status is because whether good or bad, he forced the public and the medical field to look at the completed research regarding vaccinations (Sears, 2007). This review of research helped people take the care of their children more seriously and become the biggest advocate for their children's safety.

Growth in Research Regarding Causation and Markers

Overall growth in research from 1980-2013 has touched on many different avenues of causation and markers. Different areas from neurological identifiers to genetic components as well as linkage to prenatal concerns or exposures have all been researched developments in these areas and have led to certain beliefs and opinions, regarding how ASD is caused or determined (Stromland et al., 1994). These various avenues of exploration have basically identified that more research needs to be completed in these areas because each area may hold more current information and lead to the identification of the true cause. These areas of causation and identifying markers can all be used as areas to consider for further research. Until then, table two has been provided

for the reader as a means to collectively explore a few of the major sources who have completed research in these areas as well as what their findings were and what can be studied in future research efforts.

Until a true cause has been determined, further research in all of these areas will still need to take place to validate any of the findings as pertinent research in the ASD field. Even with no definitive causation, the more research that is completed and the more focus that takes place in the area of ASD, will benefit the eventual discovery of the cause. All of these factors will help society produce more independent and successful people who are affected by ASD.

Table 2 takes a few of the areas discussed as possible factors in the cause of ASD and it declares these areas as areas of recent interest. The areas are defined as what was researched, what was found from this research and what will need to be studied in the future in these areas.

This is a small compilation of studies that highlight the areas that have been looked at for causation during this time period (Bartlett et al., 2012; Bauman, 1996; Rahbar et al., 2012; Reichenberg et al., 2006; Warburton et al., 2000).

Table 2

Possible Factors in Causation: Research, Findings and Needs

Areas	Items Researched	Findings	Needs
Neurological Findings	<ul style="list-style-type: none"> Neurological difference in typical brains vs ASD brains Defining characteristics of the brain Similarities between the ASD brains (Bauman, 1996). 	<ul style="list-style-type: none"> There are indeed differences. Differences found in cell loss, cell packing Reduced cell size Effectuated limbic and cerebral systems (Bauman, 1996). 	<ul style="list-style-type: none"> What do these neurological differences mean for the future? What changes do they mean for people with ASD in regards to treatment? Is this a future outlet to help an earlier diagnosis?
Maternal and Paternal Age	<ul style="list-style-type: none"> Does either or both ages of parents cause or determine whether or not the child will have ASD? (Rahbar et al, 2012) 	Both ages affect the chances of having a child with ASD (Reichenberg et al., 2006).	<ul style="list-style-type: none"> Variables have to be determined now regarding ethnicity, family history, pre-natal health care etc. (Reichenberg et al., 2006).
Genetic Links/Prenatal Signs	<ul style="list-style-type: none"> Is there a genetic component that causes ASD? If other family members have ASD or other developmental issues, is there a connection to having a child with ASD? Genetic markers on Chromosomes (Warburton et al., 2000, Bartlett et al., 2012). 	<ul style="list-style-type: none"> There have been links in families that show people with language issues and people with social awkwardness These findings were noted to also lead to chromosomal differences and/or markers too (Bartlett et al., 2012) 	<ul style="list-style-type: none"> Finding specific markers that can be detected as indicators of ASD.

What Does This Mean for Schools?

All of these areas discussed in this chapter have not only had influence on the medical field, but these changes in the medical field over time have changed the way educators look at the need for varying services. The pioneers discussed have succeeded in demonstrating to medical professionals and educators that people with ASD need services and with proper support and treatment they can be productive, fulfilled individuals who make wonderful contributions to society. The research that has been

completed by these individuals has demonstrated for today's educators what needs to take place in the classroom in order to better assist people with ASD. The refining of the diagnosis process has also helped educators identify students who may have not been diagnosed properly or who have fallen through the cracks and have never received a diagnosis at all. Placing a name with characteristics of a disorder and trying to find not only a cause, but a method of how to best help people with ASD to prosper is what ASD advocates, parents of people with ASD and the people diagnosed with ASD themselves could request. Forward movement in the medical field means forward movement in academics, in school support, treatments, and post-secondary support needs. The goal of educators is to provide the foundation for a productive future for students with ASD and advances in the medical field over time and in the future is what will help to make that happen.

CHAPTER IV
PIONEERS AND ADVOCATES FOR ASSESSMENTS FOR
AUTISM SPECTRUM DISORDER

Chapter Description

Chapter IV will discuss the different assessments that were created to make the diagnosis of ASD a more clarified and standardized process and the influences these assessments have had on the evolution of the ASD diagnosis from 1980 through 2013. The chapter will include the following assessments: the Checklist for Autism in Toddlers (CHAT), the Diagnostic Interview for Social and Communication Disorders (DISCO) formerly known as the Handicap Behavior and Skills (HBS), and the Childhood Autism Ratings Scale (CARS). Chapter IV will also discuss the influences on the statistical increase in the diagnoses of ASD and what this increase has meant for the schools. Along with the specifics of what these assessments have contributed to the diagnosis process, the pioneers and advocates themselves will be discussed in order to explore their reasoning for creating these assessments and what they hoped to gain from the creation of these diagnostic tools.

The pioneers and advocates of these assessments will include Simon Baron-Cohen (creator of the Checklist for Autism in Toddlers-CHAT), Lorna Wing and Judith Gould (creators of the Diagnostic Interview for Social and Communication Disorders-DISCO formerly known as the Handicap Behavior and Skills-HBS) and Eric Schopler and Robert Reichler (creators of the Childhood Autism Ratings Scale-CARS). Each of

these pioneers and advocates has advanced a specific rationale for the development of each assessment and each rationale has had an influence on or has helped to change the diagnosis of ASD. The chapter will conclude by explaining how these diagnostic criteria have affected the school systems and have helped to more effectively serve the educational needs of individuals with ASD plus improve their ability to cope in society.

Pioneers/Assessments

Simon Baron-Cohen/CHAT

Simon Baron-Cohen was chosen by the researcher as one of the pioneers of assessment because of his extensive work in developing and researching the causation for autism, as well as the diagnostic criteria for autism (Autism Research Centre, 2012). He is the most well-known for his work with autism and his philosophy that autism involves mind-blindness or delays in the theory of mind.

Theory of mind is a person's ability to understand that other people have opinions, beliefs and desires other than their own and that those feelings are to be accounted for during social interaction (Bates et al., 1979). People with autism have definitive issues with this developmental area because they are very focused on their thought processes, opinions and beliefs, and it cripples them toward making appropriate social connections and interactions (Happe et al., 1996).

Baron-Cohen has done extensive research in this area with another well-known autism expert Uta Frith, who has similar beliefs about the Theory of Mind. Together through their individual and collaborative research, the development of the theory that children with autism lack joint attention and the ability to engage in parallel play was

studied and developed to greater enhance the criteria for diagnosis (Frith, 1970). Baron-Cohen's philosophy regarding the development of sound assessments, revolved around the belief that if professionals had a diagnostic tool to utilize early in a child's development, the instrument would assist them in taking note of these deficit areas, and diagnosis would not only be more helpful, but also more accurate and more decisive due to the areas of development that could be monitored as a child grows.

Based on his knowledge of some of these criteria for the autism diagnosis Simon Baron-Cohen designed the Checklist for Autism in Toddlers (CHAT) in the 1980's. Though this is not a diagnostic instrument, it is a screening tool that can be used to identify whether certain children are more at risk for developing autism depending on their current level of development. From that screening result, a parent and physician can create a plan that would help the screened child receive support if needed and qualify for further testing. He created this tool based on his overwhelming desire for testing which revealed deficit areas in children with autism or identified children with the potential for developing autism at an early age (Holroyd & Baron-Cohen, 1993). This desire came from research he had completed which found that there was a deficit area in children with autism as early in their development as parallel play is achieved (Holroyd & Baron-Cohen, 1993). He believed that if there was a visible deficit that could be assessed and measured, then, there was a need for an assessment tool to quantify these behaviors for a diagnosis. This diagnosis would in turn qualify these children for treatments to assist in these deficit areas at early stages of development.

Baron-Cohen's (1993) research suggested that the early diagnosis for autism meant that not only would people be able to understand why such deficits and behaviors existed in these children, but the children could benefit from receiving assistance to remediate these areas earlier and have a greater future potential. At the time the screening tool was developed, the youngest age at which a physician could detect signs of autism was three years (Baron-Cohen, Tager-Flusberg & Cohen, 1993). Creating this screening tool in the 1980's meant that future growth in the causation and understanding of ASD would be able to be determined based on standardized methods at a much earlier age.

The CHAT is a screening tool that is completed by parents and the primary health care worker at the age of 18 months. The areas that are examined in the CHAT are joint attention, including point to show and gaze-monitoring, and pretend or parallel play (Baron-Cohen et al., 2000). There has been some controversy surrounding the tool because a portion is observation, and the debate is that when the child is being observed, he could possibly not be willing to participate on that specific day at that specific time (Rapin, 1996). In the revised addition of the CHAT called the M-CHAT, the observation portion has been removed for this reason. The information given in the CHAT results in, either a pass or a fail response.

There are five key areas examined with all screenings and these areas are: pretend play, protodeclarative pointing, following a point, pretending, producing a point. If a child is lacking the needed skills to be determined average among their peers he would have failed all areas in the assessment. If he failed all the included areas of the assessment, it would determine that there is a high likelihood of the child developing

autism. The parents would then be asked to rescreen their child in a month, so that if the failure was due to a delay in development, a month would allow those children to catch up (Baron-Cohen et al., 2000). When Baron-Cohen et al. tested the validity of the screener he used 91 toddlers who were 18 months of age. All of the toddlers were administered the CHAT. From these 91 toddlers, four of them failed all of the areas, which resulted in them being thought to have a higher risk of developing autism. These same four toddlers at 30 months of age were diagnosed with ASD (Baron-Cohen et al., 2000). The other 87 toddlers who passed the screener went on to develop normally with no diagnosis of autism (Baron-Cohen et al., 2000).

The advantages of utilizing a screening tool such as the CHAT, is that the diagnosis and treatment for autism or characteristics of autism, can be addressed much earlier in a child's development. There are other assessments that physicians can use, however these are usually used after the age of three. The earlier information regarding autism can be collected, and the earlier interventions and therapies can be put into place if necessary.

Lorna Wing and Judith Gould/DISCO

Wing and Gould are the creators of the Diagnostic Interview for Social and Communication Disorders (DISCO) which was formerly known as the Handicap Behavior and Skills (HBS). These women were chosen by the researcher as pioneers for assessment not only because of their development of the DISCO, but because of their extensive work in the field of ASD as a whole.

Lorna Wing was an English psychiatrist and physician who herself had a daughter with autism. Her personal battle with her daughter's diagnosis and the life that she lived motivated her to find more answers regarding the diagnosis, cause and treatment of autism. What began her journey was the diagnosis of her daughter Susie with autism. Surprising to most, but when Susie was born in 1956, Wing knew nothing about autism (Rhodes, 2011). Her lack of knowledge when Susie was born was exhibited in the fact that she did not recognize the many characteristics that Susie was exhibiting. These are characteristics about which she now exhibits great expertise. She gave 40 years of her life's work to researching developmental disabilities, pertaining mostly to autism. In 1981, after speaking with Hans Asperger about her research regarding autism, Lorna Wing took his research, after he died, and combined it with her own into an educational document regarding the criteria and understanding of what autism truly was (Feinstein, 2010). This document later was recognized as the first time the term Asperger's Syndrome was ever used in coining the term for the future diagnosis and differentiation between some of the characteristics and traits (Wing, 1981).

Through this work, she was also able to differentiate the prior belief of Kanner (1943), which was that autism was a separate entity unto itself. Because of Wing's personal situation with her daughter's diagnosis of autism, she was driven to ensure that other parents never had to go through what she and her husband endured when they received the diagnosis. Lorna wanted to minimize the feelings of insecurity and a lack of knowledge she saw in parents regarding what their next step should be to get their children the best care at the youngest possible age and enable parents to increase their

knowledge base. These factors motivated her to create the DISCO and so many other helpful resources for children with autism and their parents (Rhodes, 2011).

Wing is now retired from the organization she founded, the National Autistic Society (NAS) also referred to as the Lorna Wing Center, which was the first center of its kind to offer a full service, diagnostic, assessment and advice/ planning service. This center was created again based on her experience with her daughter Susie, and how she was left helpless after determining the diagnosis. Wing created the center to prevent any other parents from having to feel like once diagnosed, there was nowhere to turn. Her center would become the place where children could be diagnosed and parents could turn for additional help and support. Wing, in her retirement, still acts as a consultant for the center.

Judith Gould is the co-author of the DISCO, and in turn was chosen by the researcher as a pioneer because of her constant work toward a better diagnostic process and her further research on autism spectrum disorder. Judith is a clinical psychologist also with almost 40 years of experience. She is currently the Director of NAS the organization that Lorna Wing founded, and she has worked with Lorna Wing for the majority of her career. Along with Wing, she played an important role in autism being considered as a spectrum of conditions and because of this she is very well written in the field of autism (Wing & Gould, 1979).

This led to the two pioneers' desire to create the DISCO, and the how and why they chose this assessment tool. When Wing and Gould (1979) began the development of the assessment, it was based solely on their research at the time and the lack of existing

diagnostic interviews available for autism. The DISCO was created as a subset to the formerly created Handicap Behavior and Skills Schedule that Wing and Gould had originally created. The DISCO was then created or added because of Wing's beliefs of the full spectrum of disabilities (Wing, 1981). What fueled this test's creation was not the differentiation of the disorder, but the commonalities of the lack of social communication and interaction of autism (Wing et al., 2002). Because of these similarities there needed to be an assessment created not only to differentiate between the severities of the characteristics of the disorder, but also to have a common link of distinction between the characteristics as well (Wing et al., 2002). The DISCO focused on the need for an assessment that addressed what each individual could and could not accomplish where other assessments have only focused on ruling autism in or out. Wing and Gould believed that in order to provide the best diagnostic information to parents, which would lead to the best therapy for the individual with autism, the test had to examine all areas of the individual's growth. They did this by ensuring that the design of the DISCO unlike the former HBS included all ages, all levels of disability and conditions on the borderline of autism.

The few things that set the DISCO apart from other assessments and why it stands out as an influential assessment throughout 1980-2013 is because it has broadened the ability to diagnose. The DISCO identifies more individuals who would have otherwise been misdiagnosed because of the lack of assessments that existed throughout this time period. The test not only diagnosed autism, but also delved more deeply into the individual's ability level and how that affects the diagnosis itself and where it falls on the

spectrum (Wing et al., 2002). The DISCO allowed for there to be one assessment that can help a diagnostician create a full picture of the individual by creating a systematic method to interpret the data presented when conducting the assessment. It takes into account the individual's development over time, however if the individual does not have an informant, then it also allows for assessing based on the current information and excluding the infancy information. The DISCO has also gone as far as to be used to identify other conditions, which may reside within autism. One example of this would be Attention Deficit Hyperactivity Disorder (ADHD). Due to the informative nature of the test, the discussion of the results leads to a very informative reporting session of the assessment's findings for each given individual. This is exactly the result both pioneers had hoped to achieve because this was what they believed to be the best outcome, not only for the individual being assessed, but also for the parents of the individual, so parents had a stepping stone to move on to, in order to cope after the diagnosis and seek support (Wing, 1979). This work was instrumental in helping parents become more knowledgeable in the field and also become more effective advocates for their child.

Eric Schopler and Robert Reichler/CARS

Eric Schopler and Robert Reichler were the two pioneers who created the Childhood Autism Ratings Scale (CARS). Of the two pioneers, Schopler was the main influence behind the creation of the assessment; however Reichler not only contributed to the creation of the assessment, but also to Schopler's research and endeavors to better clarify the diagnosis of autism. These pioneers were chosen similarly to the other

pioneers in this chapter and that is because of their extensive work and support in furthering education and diagnosis of autism spectrum disorder.

Schopler was a psychologist who was also seen as an educationalist due to his beliefs in intervention-based approaches toward autism as opposed to cognitive based approaches (Frith, 1970). Through his extensive research on autism for the Child Research Project the Treatment and Education of Autistic and Related Communication Handicapped Children, the TEACCH foundation and program was created (Mesibov, 2006). The TEACCH program assists with the education and research of autism, while also developing therapy that has been deemed effective and well known (TEACCH Autism Program, 2012). A significant focus for the TEACCH program is that the parents can be instrumental in the development and facilitation of treatments and therapies for their children. Because of this strong movement, Schopler has been defined as a pioneer and voice for parents in the care and remediation of their children. This voice is what drove him and his colleague, Reichler, to create the CARS assessment. This was an assessment they believed would lead parents and diagnosticians to a clear cut diagnosis for their child. Though not an assessment that is intervention based, Schopler, Reichler, Devellis, and Daly (1980) believed that once all other diagnoses were discounted through their assessment, a more intervention based approach to treatment could be considered once parents and physicians had a clear diagnostic result. As a side note, Schopler and Reichler did create a more intervention based assessment to be used in coordination with the CARS to support their true beliefs of well-rounded diagnoses. This test is called the Psychoeducational Profile (PEP), and it was published in 1980 and revised in 1990. It is

also widely used by many, especially educational facilities across the world, because of its ability to assess skills and behaviors once the diagnosis is made. This information provides data that can be gleaned, and that can add to a plan for behavioral interventions and educational programming in the individual's future (Feinstein, 2010).

The CARS assessment was developed to define and diagnose each individual as their individual characteristics related to autism. The scale was created by Schopler and Reichler through the 1970's, but published in 1980 to rule out other developmental disorders and mental retardation (Mesibov, 2006). The CARS assessment is currently one of the most widely used assessments for the diagnosis of autism for individuals from ages 2 years to 15.9 years of age (Mesibov, 2006). The CARS assessment included observation of such areas as relationships with family and friends, imitation, effect of the individual toward others, use of the body for communication and other purposes, relation to non-human objects, verbal communication skills, non-verbal communications skills, intellectual functioning, and the diagnostician's observations (Schopler et al., 1980).

What Does This Mean for Schools?

These assessments have helped to shape how schools have developed programming, placed students within the classroom as well as provided them with additional services to support their success throughout their school career. Children who are identified at an early age have been proven to be more productive and effective adults just simply based on the resources they have been given in school and the opportunities for support that have been provided during their growth.

Early Intervention is an important example of opportunities provided to children with disabilities. Early Intervention is a service provided through the state under Part C of IDEA. Part C requires “to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate” (*Individuals with Disabilities Education Reauthorization Act*, 2004). Early Intervention is a service plan that mandates that any and all children who have been diagnosed with a disability are to be provided extra services from which they can benefit in their development and, in turn, be better prepared for school and their future. However, these services are only funded through the state until a child turns three years of age. Therefore, the importance of assessing a child early on for needs in the area of autism is critical (Filipek et al., 2000). The earlier the assessment is completed, the better for the child because if signs and symptoms are neglected, then the services for the child will be neglected as well. This situation makes the start to school even more difficult. This is where an assessment such as the CHAT (now known as the M-CHAT) can be useful as a screener that can possibly give knowledge regarding where delays in development are present and, in turn, help direct where the child should be further assessed in case Early Intervention services can be beneficial.

Children who have been diagnosed with a disability are promised an appropriate public education that meets each child’s individual needs under IDEA. Because of this, parents should ensure that their children are provided the best educational provisions possible based on their child’s individual needs and diagnosis. This is where assessment

has become so important. Assessments such as the DISCO and the CARS provide those diagnoses and have been doing so for several years. These diagnostic assessments provide the educators with exactly what educators need to develop programming that is based on the strengths and weaknesses of the diagnosed child. The more information with which schools are provided, the more explanation of the child's needs they are given. This allows each school to take the child's diagnostic review and recommendations, and apply them to the child's needs and placement within the classroom. Without accurate assessment tools for autism, children's programming in the past has been noted to be insufficient and/or inaccurate. This injustice has unfolded through the many legal cases over this time period. Though we cannot be definitive about how much of a role diagnosis and assessment played in these cases, understanding more about each child's individual diagnosis can definitely play an important role in appropriate programming.

Often, people do not think a diagnosis is necessary because the schools can perform what is called an eligibility assessment for each student. According to Aspy and Grossman (2007), there is a distinct difference between assessment completed for diagnosis and assessment completed for eligibility (see Table 3). When the school has completed an eligibility assessment for a student with autism it is based on the outside diagnosis of the student usually completed by a medical professional. Without this professional diagnosis, a school system cannot declare that a student has autism. It is the responsibility of the school, if they are in need for the diagnosis, to be designated to provide it for the family at no expense to them through an outside agency. The eligibility

assessment is performed strictly to enhance the student's schooling and provide him with the appropriate programming necessary for his individual success within the classroom and through necessary therapies.

Table 3

Diagnosis versus Eligibility

Diagnosis	Eligibility
Based on a set of criteria (e.g., DSM-5).	Based on federal law (IDEA).
Refers to a specific disorder (e.g. autism spectrum disorder, asperger's disorder).	Refers to a broad disability category.
Used in a private sett	Used only in public school systems.
May be determined by an individual or team	Must be determined by a team.

Once an outside assessment has been completed by a medical professional and the child has been diagnosed with autism, the next step is having the school perform the child's eligibility assessment. Once that is completed by a team of professionals from the school, then the Eligibility and Individual Education Plan (IEP) meeting is held to report the findings (Lord, McGee, & National Research Council, 2001). From these findings, the IEP team which includes all educational professionals involved in the Eligibility Assessment, and the student and parents will come together to report and discuss the findings. From these findings the appropriate educational programming for the student is determined based on the outside diagnosis and the eligibility assessment.

Concluding, assessment is one of the key factors in educational programming. It is critical to determine a child's diagnosis early and accurately, so that there is the best

possible outcome from the earliest possible age for the child. Once detected, autism can begin to be treated to develop positive behaviors and development that will continue to impact each child's growth process throughout his life in the educational system and post-secondary school when he goes on to live a healthy and productive life.

CHAPTER V

PIONEERS AND ADVOCATES FOR THERAPIES AND EDUCATIONAL
TREATMENTS FOR AUTISM SPECTRUM DISORDERS

Chapter Description

Chapter V will discuss the pioneers and advocates who have helped develop the different therapies and treatments that have been used in the therapeutic setting, as well as the educational setting from 1980 to 2013. In addition to the pioneers and advocates, this chapter will also discuss the evolution of therapy and educational treatments, and how their focus has changed over time from a behavior modification approach, to an increased understanding of the need for improved social skills in the areas of social interaction and pragmatic communication.

Some of the specific therapies and educational treatments for ASD that will be discussed in this chapter are the Treatment and Education of Autistic and Related Communication Handicapped Children program (TEACCH), the Lovaas method, Social Stories, Social Thinking and the Gluten and Casein Free Diet. Each of these therapies and educational treatments is very well known, and each has been proven effective by their own research theories. The discussion of these programs will include a narrative about the pioneers and advocates of each therapy and educational treatment. The creators of these therapies and educational treatments are Lovaas, creator of the Lovaas method, Schopler, creator of the TEACCH program, Gray, creator of Social Stories, Garcia-Winner coined the term social thinking and developed educational therapy tools

revolving around the concept of social thinking, and Reichelt, creator of the Gluten and Casein Free Diet. These programs will be discussed to help review the rationale for the creation of these therapies and educational treatments, to examine the effectiveness of each rationale and to describe how each therapy and educational treatment has changed and influenced the evolution of ASD. The discussion of this evolution will also aid in the creation of an improved understanding of how school systems have attempted to incorporate some of these therapies and/or educational treatments into their curriculum.

Pioneers/Therapies and Educational Treatments

Ole Ivar Lovaas /The Lovaas Method

Ole Ivar Lovaas is a clinical psychologist who was an Assistant Professor at the University of California for the majority of his career. He spent approximately 40 years of his career on ASD research and pioneered what is now known today as an influential therapy treatment for ASD called the Lovaas method (Fox, 2010). Lovass is recognized as one of the first people to realize that behaviors related to ASD were able to be changed or modified. This came from Lovaas's research on Applied Behavior Analysis (ABA) (Sallows & Graupner, 2005).

ABA was known in its early stages as behavior modification. Behavior modification was thought to be a therapeutic method in which the behavior was modified without addressing what was ultimately causing the behavior (Cooper et al., 1987). Lovass aspired to find a therapeutic treatment that not only changed the behavior, but addressed the cause and helped to either remediate that cause or at least considered the origin. The Lovaas method of therapy treatment is a form of the ABA method.

Lovaas created many research studies that focused on coding behaviors according to their placement regarding antecedents and consequences relating to the specific problem behaviors (Eikeseth, Smith, Jahr, & Eldevick, 2007). Lovaas had also been known to include shock therapy in his early research in ABA therapy treatment. However, after 1973, he had found that this treatment was not only unnecessary for successful behavior change. It was ineffective and had no successful long-term effects on behavioral change (Eikeseth et al., 2007). Due to these findings, Lovaas proceeded to conduct several more studies that resulted in gains for the current Lovaas program. These gains resulted in findings that were beneficial to patients' long-term success. These gains were noted as early intervention therapy treatments in pre-school years, as involvement of parents during the intervention, and as implementation of the therapeutic treatment within the home as opposed to a treatment center. These findings have shaped the Lovaas program to make it what it is today.

Today's Lovaas method should begin in a child's life as early as two and no later than 12. The treatment for young children is formulated through a play-based therapy model based on the age and attention of the child while applying what is called discrete trial training (McEachin, Smith & Lovaas, 1993). "Discrete trial training (DTT) is a one-to-one instructional approach used to teach skills in a planned, controlled, and systematic manner" (Remington et al., 2007, p. 422). The use of this sort of therapeutic formatting was believed by Lovaas to be the most effective choice because it taught children with ASD a format that had a definite beginning and end. The discrete trial training process enables the child to receive positive reinforcement while also learning the skill

acquisition and maintenance needed for generalization of learned skills or behaviors (Sallows & Graupner, 2005).

The following is the belief system on which the philosophy of the Lovaas treatment method is based:

Positive Interactions: these are first developed through the use of favorite activities and responding to any attempts to communicate.

Motivation: is encouraged through the use of familiar materials and child-specific reinforcement techniques.

Success: is promoted through positive reinforcement of successive approximations plus prompting and fading procedures.

Parental Involvement: this is critical. Parents are empowered through training and collaboration to create an environment in which treatment is provided during most of a child's waking hours, at home, at school, and in the neighborhood.

Requesting: is a skill that is developed as early as possible.

Language: Learning to talk and understand vocal language is considered a fundamental part of social development.

Imitation: this is also crucial, allowing a child to learn by observing other children learning.

Social Interaction and Cooperative Play: are integral to treatment. Facilitated play occurs first with siblings and then with peers during play dates and at school. (Lovaas Institute, 2012, para. 5)

The intensive therapy for the younger child is usually conducted on an hourly regimen every week increasing as the child grows (McEachin et al., 1993). The goals for this population can be to decrease stemming behaviors, increase communication, decrease reactions to sensory stimulation and requesting (McEachin et al., 1993). According to Lovaas (1987) himself, the work done in his study with children with severe ASD and the basis for intense treatment measures, was identified when he stated

Given a group of children who show the kinds of behavioral deficits and excesses evident in the pretreatment measures, such children will continue to manifest similar severe psychological handicaps later in life unless subjected to intensive behavioral treatment that can indeed significantly alter that outcome. (p. 9)

As the child progresses in age, the hourly therapy regimen and the intensity and structure of the treatment increase. The treatment becomes one on one and very structured, so that the child knows what is expected from day to day. As the child ages, the goal of the therapy is to incorporate his or her daily routine into the therapy in order to mirror the routines of their same aged peers to facilitate more socially appropriate interactions (McEachin et al., 1993). The last phase of the age-based therapy treatment focuses on the child's ability to learn in groups and develop relationships with other children. Structured time for therapy may be increased with a decrease in play breaks during therapy treatment (Jacobson, 2000). The eventual goals for this stage of therapy treatment are to facilitate carryover into the child's natural environment, to include them at school, and to have the child participating in family based and community based events and skills (Jacobson, 2000).

Due to Lovaas' (1987) constant desire to conduct research to demonstrate the effectiveness of his theories and programs, the Lovaas method of therapy treatment is also one of the few treatments that is considered evidence-based and has completed extensive research to prove its efficacy in this format of treatment (Lovaas Institute, 2012). There are still people who do not think the method is effective and believe that there are several variables that need to be analyzed further. However the basis for treatment is documented, and because of this evidence, it has been deemed a therapy treatment that is recognized as evidence-based.

Eric Schopler/Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) Autism Program

Schopler, who is seen as an educationalist due to his beliefs in intervention-based approaches toward ASD as opposed to cognitive based approaches (Frith, 1970). Through his extensive research on ASD for the Child Research Project, the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) foundation and program were created (Mesibov, 2006). In 1976, he became the director of TEACCH. This position allowed him to utilize his research confirming that ASD is a developmental disability and not the psychogenic condition that it was declared in past history (Feinstein, 2010). The TEACCH program assists with the education and research of ASD, while also developing therapy treatment that has been deemed effective and well known. A large component of the TEACCH program supports the premise that parents can be instrumental in the development and facilitation of therapy treatments for their children based on the respect of the *autism culture* that has been engrained in the program (Mesibov, Shea & Schopler, 2004). The *autism culture* means that the program has a respect for the disorder, and it is not looking to remove it from the person, but rather teach the person with ASD to live a productive life despite ASD. The TEACCH program prides itself on the belief that ASD is a lifelong condition, and although the program can not completely remediate the disorder, it can help to develop and manage the strategies that will make life easier and promote a more neuro-typical existence (Mesibov et al., 2004). Because of this strong movement and belief

system, Schopler has been defined as a pioneer and a voice for parents in the care and remediation of their children with ASD.

TEACCH was deemed the first comprehensive state-wide community-based program of services for children and adults with ASD and other similar developmental disorders (Mesibov et al., 2004). The main goal of the program is to help those with ASD to have easier and more productive lives by decreasing their less preferable social behaviors. TEACCH is a program that is based on visual learning. Individuals with social deficits like ASD benefit most from a visual learning program which includes structure and predictability. TEACCH bases its practices on taking the social deficits of the people in its program and modifying their behaviors while adapting them to what is functional in real-life. Other programs use an approach that seeks to take the less desirable social behaviors and remove or remediate them completely (Panerai, Ferrante, Zingale, 2002). The program also focuses on the principle of *structured teaching*. This principle, in essence, means that the program takes what each person's ability level is plus their learning characteristics, and strives to help them deal with the world around them based on this ability level. Ultimately, this creates the most independence, possible with each person (Mesibov et al., 2004). When referring to ability level in regards to the TEACCH program, it is important to note that the adaptations come based on the person, but the actual therapy treatment itself remains the same for each person. Because TEACCH began as part of a behavioral therapy, it focuses on the *typical* behaviors of people with ASD and has recently tried combining cognitive components as well (Sallows, 2000). With this base in behavioral therapy, the TEACCH program attempts to

determine why these behaviors exist with each individual person. Once they have determined the reasoning, which the program believes is mainly due to a lack of understanding in the person with ASD, a lack of communication skills or an over stimulation of sensory information, the program helps the person with ASD in learning how to express himself, which in turn decreases the negative behaviors (Watson, 1985).

TEACCH has been widely recognized as an effective treatment, but it has not been fully identified as evidence-based. Most of its research has been conducted using children, which it describes itself as a therapy treatment for all ages. When compared with the Lovaas (1987) program or Applied Behavior Analysis (ABA) therapy, it does not have many long-term studies that have been completed. Even though this is true regarding long term research, the effects of the TEACCH program have been deemed influential on the shaping of the therapy treatment of ASD over the years (Schopler & Mesibov, 1994). “The guiding concepts of the TEACCH program are as follows: improved adaptation, parents collaboration, assessment for the individualized treatment, structured teaching, skills enhancement, cognitive and behavioral therapy and general training” (Panerai et al., 2009, p. 875).

Carol Gray/Social Stories

Carol Gray is the Director of the Gray Center for Social Learning and Understanding (Gray Center, 2012a). This center was first created to connect individuals with Autism Spectrum Disorder (ASD) and the people with whom they interact in a more effective manner, in order to help them to more effectively utilize their social skills. Gray developed this non-profit organization because of her passion in this area. She also

wanted a facility that could work on addressing the areas of deficit that people with ASD encountered. These areas of deficit are social interaction and social communication. Gray started her career as a teacher of students with ASD, but quickly realized her passion and work could be better served by opening the Gray Center. The Gray Center is where Gray's career began with her developing the work for which she is now known. She is most widely known for her work with Social Stories, which was created in 1991. She believed social stories were the key to helping people with social skills deficits. The person with ASD would be faced with a situation, and because of their deficits, they would act out. Their actions were based on what they thought the intentions of others were, but were often misunderstood (Attwood, 1997). Then, this would result in the person exhibiting inappropriate social behavior because the skills to cope with what was in front of him or her were absent.

Deficits in social interaction and the understanding of pragmatic language are the main deficit areas of people with ASD. Social stories have been a staple in therapeutic treatment for ASD for years now, and it began with the need for children to become socially invested in what they were learning in order for carryover of these taught skills to take place in the person's everyday life. Social stories are situational stories that highlight social cues and responses, and this highlighting aides in the understanding of how socially interactive tools work together to create effective communication (Fullerton, Stratton, Coyne, & Gray, 1996). When writing a social story, it is effective to include the perspectives of the child and the people involved when developing the story. This way, the student can relate the actual occurrence to the people and surroundings they are use to

and can relate to it more effectively (Lorimer, Simpson, Myles & Ganz, 2002). Gray (1997) developed certain types of sentences and formatting for the social stories, so that it was a format the teachers, parents or therapists could follow and create consistency every time they needed to create a social story. Whether it was for the understanding of good behavior, bad behavior, social communication or misunderstandings, the format would be one in the same with the only changes being the situation. The following is a brief summary of the suggestions for writing the best and most effective social story.

There are four types of sentences used in writing social stories:

1. Descriptive sentences: objectively define anticipated events where a situation occurs, who is involved, what they are doing, and why (e.g., When people are inside, they walk).
2. Perspective sentences: describe the internal status of the person or persons involved, their thoughts, feelings, or moods (e.g., Running inside could hurt me or other people).
3. Directive sentences: are individualized statements of desired responses stated in a positive manner. They may begin “I can try...” or “I will work on...” Try to avoid sentences starting with “do not” or definitive statements (e.g., I will try to walk in inside).
4. Affirmative sentences: sentences that help explain abstract situations, often through the use of analogies. (Gray, 2004, p. 52)

Social stories should have three to five descriptive, perspective and/ or affirmative sentences for each directive sentence. They should avoid using too many directive sentences because this may cause the reader to only see directives instead of the social and environmental cue information. The author should write in first person and at the reader’s skill level (Gray, 1994). Pictures should be used to supplement the written expression of the story (Fullerton et al., 1996; Gray, 1994, 1997, 2000). Gray (2004) suggested that following these guidelines will allow the person with social deficits to

become accustomed to the format. This familiarity will help them to begin to realize how their behavior affects others, and also what to expect when faced with a social situation that is confusing or often times distracting to them.

There have been mixed reviews on the social story philosophy of therapy treatment. When people are trying to discuss whether or not it is an evidence-based form of therapy treatment, the reviews are mixed (Whitehead, 2007). Some people have used them and found they are wonderful tools. They use them to explain to people the rights and wrongs of social conversations, while also including explanations of the misunderstandings of social interactions (Moore, 2004). However, some teachers, therapists and parents find social stories to be for a younger population only. There are beliefs that social stories are lacking the interactive piece of social therapy. The story itself does not interact with the person. Therefore, when the person with social deficits is faced with the same social situation months or years later, the person may find because the behavior from the story has not been experienced in real-life interaction, the carryover into a real-life setting may be non-existent (Whitehead, 2007).

Michelle Garcia-Winner/Social Thinking

Garcia-Winner (2000) is a Speech-Language Pathologist whose career focuses on the specific area of social cognitive deficits in ASD. Garcia-Winner (2002) began her interest in ASD early in her career. Her interest in this topic was one of the main reasons that drove her to develop the therapy treatment of social thinking. Due to her experience as a Speech-Language Pathologist, she was able to use her schooling and life experience to refine some of her therapy techniques to encompass a client with Autism Spectrum

Disorder's (ASD) areas of social deficit. Her original therapy treatment ideas, developed from her past experience with ASD, but soon developed into a therapy style that was directed more toward students who were intelligent enough to one day be independent, but had many social deficits that could impair their ability to not live life to the fullest.

Her extensive research in the 80's, led to her creating the term *social thinking* in 1990's. She developed a center called the Social Thinking Center where her therapy of social thinking is practiced with clients having social deficits. Garcia-Winner's (2000) main desire is to ensure that these therapy strategies are easy enough for parents, teachers and therapists to use and to develop practical adaptations for these clients to use in their everyday lives. Garcia-Winner (2013) has published more than 20 books on social thinking and she speaks nationally and internationally regarding the social thinking therapy technique. In 2008, she was awarded a certificate of Special Congressional Recognition for developing this treatment approach.

There have been many therapies developed over the years for clients with ASD, but a lot of them have been proven to be lacking some of the components for carryover into the real-life setting (Koning & Magill-Evans, 2001). Social thinking has become a therapy that has proven to have results that are based on the actual interaction as it is happening, therefore, becoming much more engrained into a person with ASD's natural life setting. Social Thinking is a therapy treatment that was originally designed for students who had ASD and who were above average intelligence, but who struggled with social skills and social language (Ozonoff, Pennington & Rogers, 1991). The basis for

this therapy method is for a person with ASD to give thought to others when they are communicating.

ASD is a very self-oriented disorder in which a person can focus only on his side of a conversation, as well as, a topic in which they are interested in neglecting any other conversational partner involved (Feinstein, 2010). This is where the social language deficit is demonstrated and where conversation lacks all social components because it is one sided. This means that a person with ASD would need to consider the intentions and thoughts behind a person with whom they were interacting. The interaction could be conducted in person, over the phone, or via social media etc. Garcia-Winner has found that this therapy treatment can now also help all areas of disabilities with social components for example, Attention Deficit Hyperactivity Disorder (ADHD) and Learning Disabilities. She has also noticed that with the rise in communication America's youth today via social media and phones that even neuro-typical students can benefit from some of her therapy material because they too can be missing and/or omitting social components of conversation.

The 12 core points of teaching social thinking are as follows:

1. What are social skills?
2. What are the origins of social development? Is there an age when our social development stops?
3. In what areas of social thinking do students with social cognitive challenges struggle? The ILAUGH Model remodelled
4. What impact do weaknesses in social conceptual information have on learning the Common Core State Standards?
5. When do we use social thinking and related social skills? How do we approach teaching these skills?
6. How can cognitive behavior therapy address teaching social thinking and related social skills?

7. Do all those with ASD-SCD benefit from the same teachings? The Social Thinking-Social Communication Profile (ST-SCP)
8. Who is responsible for teaching social thinking and related social skills? Is the same set of teaching techniques relevant for all persons with ASD and related social learning challenges?
9. What is a framework for teaching social thinking and related skills?
10. What are some guidelines for teaching social thinking and related skills to group of students?
11. How does social teaching fit into what we typically call "education"?
12. What are evidence-based practices? How do they apply to teaching social thinking and related social skills? (Garcia-Winner, 2013, p. 125)

These 12 core points of teaching social language have been Michelle's focus and drive for improvement of social language because they encompass all aspects of real-life settings for a person with social language deficits. An example that is used for the curriculum of social thinking is taking the information we know as socialized individuals and sharing and teaching it to people with social deficits. By imparting this wisdom on the person with social deficits, he is able to explore and learn the expected responses from us, while relating those responses and practicing them. This practice will aid in their responses becoming more natural, so when he encounters these situations on a day to day basis, he is able to recall and utilize these techniques (Garcia-Winner, 2002).

Garcia-Winner (2007) believed that part of the major breakdown for people with ASD and social deficits in general is that there is a *hidden curriculum* within our social language and these people cannot decode this curriculum independently (Garcia-Winner, 2007). It is because of this *hidden curriculum* that the social breakdown takes place. Hidden curriculum is discussed as social cues and behaviors that the neuro-typical person takes part in spontaneously because he was able to acquire it at a young age (Solomon, Goodlin-Jones & Anders, 2004). An example of part of the hidden curriculum would be

when a neuro-typical person gets into an elevator, he would know to probably not carry on a very loud and lengthily conversation with the individuals in the elevator. However, a person with social deficits might find the confinement of the elevator, as an opportunity to share some information he has learned recently regarding elevators and the operation of elevators because no one has ever told them differently (Garcia-Winner, 2007).

Garcia-Winner's (2007) thoughts are that the more the person with social deficits is taught to think about and constantly consider the feelings and emotions of others, the more he will begin to do so more naturally as it becomes more of a rote behavior as it is for neuro-typical people. She also discusses thinking with your eyes, listening with your eyes and that looking equals thinking (Garcia-Winner, 2007). Very similar approaches mention eye contact, but Garcia-Winner's thinking with your eyes, actually discusses a much more in depth version of why having eye contact is necessary and what it adds to the process of social thinking and understanding the other social partner's intentions (Garcia-Winner, 2002). This is what has made social thinking the newest and most relevant therapy that schools and therapists are using today. People are looking for applicable therapy techniques that have easy carryover, so they can see improvement on a day to day basis. This therapy among others is beneficial to people with ASD, however the carry-over into the natural environment is what has helped change the framework of therapy for people with ASD, and this benefit has motivated people to utilize social thinking over other therapies.

Even though there has been research conducted on Gray's and Garcia-Winner's therapy treatment style, there are still skeptics about the efficacy and carry-over of social

skill therapy treatment into the daily life setting of people with ASD. Researchers have tried to help these therapies more clearly define for teachers, therapists and parents who are servicing people with ASD, a sort of rubric that will help structure the beginning of the therapy, plus the focus and the outcome of therapy. This rubric can provide a guideline to success, but also be careful not to make the therapies be too rigid so they are all the same. These therapies pride themselves on being individual to the person with ASD, however some systematic guidelines may be needed, so they are done similarly to receive the same successful outcome (Baker, 2010). Baker was able to outline some preliminary guidelines listed below, and currently researchers are continuously conducting studies, so that there is more evidence-based research on social skills therapy and its benefits. Until then, Baker outlined what he believed to be a beginning to the guidelines.

Table 4

Guidelines for Social Skill Therapy Structure

Assessment	Prioritize relevant skill goals based on input from key stakeholders (e.g., the student, parents and teachers)
Motivation	Establish motivation to learn and use skills
Initial Skill Acquisition	Teach skills using strategies that match the student's language, cognitive and attention abilities
Generalization	Coach students to use the skills in natural settings and capitalize on interests and preferences
Peer Sensitivity Training	Target typical peers as necessary to increase generalization, reduce isolation, increase opportunities for friendship and decrease bullying.

Source: Baker, 2010, pp. 8-11.

Kalle Reichelt/Gluten and Casein Free Diet

Karl Ludvig Reichelt also known as Kalle Reichelt is a Norwegian doctor and also a medical researcher. He is best known for his research beginning in 1991 concerning the effects of the gluten and casein free diet as a treatment for people with ASD. He discovered what was believed to be a link to the consumption of gluten and casein and the traits of ASD. Based on Reichelt's early research he discovered that there was a commonality between the peptides in the urine of people with ASD after consumption of gluten and casein, therefore creating a certain opioid effect on the person and distorting their behaviors (Reichelt et al., 1981). This led to the theory that these two substances are not as easily digested by people with ASD, and they could possibly be more harmful to their brain functioning, therefore leaving an adverse effect on their bodies. These findings came at a very interesting time when there was not much discussion of ASD and not many readily available or successful treatments for ASD. Trying to alter diets to cure different ailments was not a new phenomenon among researchers and scientists alike. Dating all the way back to 1970, Benjamin Franklin Feingold completed work that found diets including salicylate and additives such as dyes and artificial sugars increased behaviors in children associated with Attention Deficit Hyperactivity Disorder (ADHD) (Elder et al., 2006). His research indicated that 50% of the children tested had decreased behaviors when these substances were removed from the diet of a child who had ADHD or learning disabilities (Elder et al., 2006). Because of this finding, people looking for alternative treatments for ASD flocked to the possibility that the gluten and casein free diet may work for people with ASD.

These claims have been very controversial because there have not been many studies conducted which have demonstrated that the diet is effective or that gluten and casein have had significant effects within or without being in the diet of a person with ASD. Therefore, why has this diet been so widely used and tried by many people with ASD? The belief in the diet stems from the understanding that people with ASD often have gastrointestinal abnormalities. These abnormalities allow unusual amounts of digestive substances to affect the gut lining of the person with ASD. Neuro-typical people do not have these unusual amounts (Elder et al., 2006).

Today, there are still battles to determine whether or not this diet is considered a legitimate treatment for ASD and behaviors of ASD. The successes have been so individualized that some people swear by a connection between the diet and ASD, and some people do not believe there is a correlation at all. Research on the diet has been flawed in years past, and because of these results, not much research has been conducted that can completely generalize the effects of the diet as the sole source of a change in the behavior of a person with ASD (Alpert, 2007). The research is so hard to validate since the study needs to be double-blind because of the outside factors which can tamper with the results. However, many parents do not want their children to participate because the double-blind studies require one group to re-enter gluten into their diets, and the parents who believe in the diet do not ever want the success being tainted for experimental purposes (Alpert, 2007). Due to this apprehension, there is not a lot of evidence for the efficacy. This situation makes society question whether to try is treatment or to trust the validity of it. Today, people are still searching for effective treatments. Now, with the

new discoveries concerning celiac disease, and with gluten and casein-free food becoming more readily available, parents of children with ASD more likely to try the diet. This willingness to try treatments that may not have much sound evidence of success, demonstrates the dire need for researchers to find help for people with ASD.

What Does This Mean for Schools?

Often, schools think of therapy treatments as something that happens outside of the school setting. However, with the therapy treatments that are discussed in this chapter, these treatments can all happen within the school setting. This situation makes it very important for school personnel to understand the inner workings of each therapy treatment and what it means for their school. Therapy treatments for ASD have changed and progressed over time, however the one main aspect that they have all encompassed is the need to help people with ASD live more productive and socially capable lives. The school system is definitely one avenue on which this treatment can be dispersed in a manner like Physical Therapy, Occupations Therapy, Speech-Language Therapy and Music Therapy. Inclusion into the regular education classrooms is frequently the ultimate goal for all students and for the parents of these students with ASD; however research also agrees. A study was conducted regarding the advantages of including students with ASD. The study noted that students with ASD also benefit from having interaction with their regular education peers.

For example, researchers have documented that students with disabilities,

including students with autism, who are fully included (a) display higher levels of engagement and social interaction, (b) give and receive higher levels of social support, (c) have larger friendship networks, and (d) have developmentally more

advanced individualized education plan goals than their counterparts in segregated placements. (Hunt et al., 1994, p. 210)

With that being said, there are also studies like the one completed by Evans et al. (1992) that show when ASD students are included, they have to be watched very closely. Care has to be taken so that their interactions are not just in the direction of the receiving social interaction while they never participate in the initiation of conversation. Otherwise, some of the benefits of socialization with their regular education peers can be lost (Evans et al., 1992; Hunt et al., 1994).

The above therapies are deemed necessary for the school to perform once the Individualized Education Plan (IEP) team has recognized the therapy treatment as a need for the child. Once again, an eligibility meeting takes place and reports are submitted by the professionals who are requesting the therapy. Then the IEP team proceeds from these diagnoses concerning how these therapies will be implemented. As mentioned, Lovass (1987) and TEACCH are both therapy treatments that need intensive hourly therapy during the child's daily routine. This would require the school to not only hire someone who specializes in this therapy technique, but also needs to allow for academic flexibility concerning how the child's academic classes and needs will be met. The schools also have to take into consideration any additional equipment that may need to be provided to fulfill the child's therapy treatment and any liability that they may face regarding the specific type of therapy treatment for which the school could be held responsible. The two social skills therapy treatments are implemented by a Speech-Language Pathologist, and would take place during the time that speech-language therapy would be given. These therapy treatment minutes would again be determined by the therapist as well as

the IEP team at the child's IEP eligibility meeting and implemented during the normal school day. The teachers could also be a part of this therapy treatment because it involves the child's social skills within the student's everyday setting. The teachers would be required to understand the development of the social therapy in order to help facilitate progress and carryover in the most effective manner.

The gluten and casein free diet would have an interesting component to it in order for it to be implemented at the school. Children eat lunch at school, but to place a school professional in charge of what they eat can be a very grey area of responsibility. This special accommodation can be placed as an accommodation within the IEP, however the school would need to assign someone to the child to ensure that the special diet sent from home was eaten by the student and to ensure that the child did not eat any treats or school snacks that were compatible with the diet. Again, the school would have to research liability for this measure and devise a plan involving the parents for the lunch time routine. The school would also have to take into consideration issues such as the child refusing to eat the specific lunch or the home forgetting to provide the student with a lunch.

Today, therapy for ASD is becoming more popular because of the rise in diagnosis. Some of the therapy treatments mentioned above have been around for quite some time, but have evolved as to the amount and the extent to which they now exist. They have also changed from a focus on the behavior management portion of the therapy to a focus on the social interaction of the child with others. This change in focus is designed to help facilitate a more neuro-typical existence for the child as well as a more

effective transition into society and to improve the ability of the child to eventually become completely independent. The therapy treatment utilized with each child with ASD depends on the severity of the ASD as well as the ability level of the child (Evans et al., 1992; Hunt et al., 1994). This situation affects the school system because the school is where this ability level is often times gauged, and is also often the place where most of a child's skills are determined and needs are met.

CHAPTER VI
PIONEERS AND ADVOCATES FOR INCREASING THE REGULATIONS,
RIGHTS, FUNDING AND SOCIETAL ACCEPTANCE FOR AUTISM

Chapter Description

Chapter VI will discuss the regulations, rights, funding, and societal acceptance related to the advancement of ASD that evolved from 1980-2013. In addition, the contributions of the pioneers and advocates who advanced this evolution will be discussed. The pioneers' and advocates' influences in these areas are individualized contributions. However, each contribution, when put together, has contributed to the major advancement that ASD has made over the time period from 1980-2013. Without each pioneer's contribution, the advancements that have been made to improve the quality of life for people with ASD would not exist.

Pioneers of Regulations

Regulations have been developed over time for ASD to ensure that ASD is recognized as a disorder. These regulations have helped to recognize and improve treatments for individuals with ASD, and assisted in defining regulations regarding services needed to address the needs of individuals with ASD. One of the most well-known regulations regarding those with disabilities is the Individuals with Disabilities Education Act (IDEA) which also was amended to include people with ASD. IDEA started as the Education for All Handicapped Children Act (EHA), but in the 1990's was renamed IDEA because the focus became more individually based as far as rights and

services were concerned (United States Department of Education, 2007). The EHA, had been more focused on specific disabilities and ensuring that children with disabilities would receive a Free and Appropriate Public Education (FAPE) (United States Department of Education). EHA was then amended and became IDEA, which began to be more individually focused discussing treatment and diagnostic parameters and became more informative toward the individual by placing more specific mandates for the individual, so that educators, service providers and parents knew how to provide the best education possible for people with disabilities. This can be noted when the word Individual was added to the title.

In 1997 and 2004, when IDEA was amended further in order to more clearly specify what parents, educators and students should understand about the current rights, regulations plus services which a person with disabilities may be able to receive as mandated by the United States and each individual state as it pertains to them. Prior to 1997, ASD was not recognized specifically in IDEA as its own category (Turnbull & Turnbull, 1998). When ASD was added as a category for reporting statistics to the United States concerning the utilization of special services within the schools, this opened the doors to many new services and treatments which had not been offered before. Prior to this addition of the category, there were no mandated regulations which officially secured the needs of people specifically identified with ASD (Turnbull & Turnbull, 1998). In the 1997 amendments to IDEA, the ages of youth served by this regulation were more clearly defined and specifically written, so that services would be initiated at a much younger age.

One of the pioneers responsible for signing these amendments was President Bill Clinton. President Clinton signed the law that amended and reauthorized IDEA in 1997 therefore, ensuring that all agencies around the country will have to abide by these mandates, which improve the rights of people with disabilities. All of the changes that occurred with IDEA focused the priorities of the verbiage to better specify roles of parents, general educators, and students in the Individualized Education Process (IEP) (Turnbull & Turnbull 1998). The regulations that were amended were added and/or changed to include a better focus on curriculum for students with disabilities including students with ASD. Using this strategy, the exposure to the general education curriculum was focused to ensure that children with ASD had the opportunities to experience the same educational information that the regular education student experiences in the classroom (Turnbull & Turnbull, 1998). From the revisions that were made, agencies were mandated to create an annual plan that describes how the state and their schools will institute these regulations. This process ensures that states are in compliance with IDEA for the betterment of all people with disabilities including people with ASD. Beside the addition of ASD being recognized as a specific category under IDEA, the sub categories were amended for all people with disabilities, especially people with ASD. The amended categories were as follows: The evaluation and re-evaluation process, revisions to the content of IEPs, revisions to the requirements of the IEP team, progress reports, no cessation of services, regular education environment regulations, the role of the regular education teacher, state and district assessment amendments, accountability and performance goals (*Individuals with Disabilities Education Reauthorization Act, 1997*).

All of these changes in regulation are beneficial for all people with disabilities, but especially for people with ASD.

Included in the amendments to IDEA in 1997 and 2004, were the mandates that a range of services be provided to infants and toddlers with disabilities, through what is now called *Early Intervention*. Early Intervention is one of the most important mandates in IDEA because it begins to initiate services for a young child with disabilities at the youngest age possible. This mandate has proven to ensure that children with disabilities receive the treatments and services they need to improve their development to the highest extent possible at the youngest age possible for the most growth possible.

These amendments are even more critical to children with ASD because many of the signs indicating that a child has ASD appear early in child development. Early Intervention will continue to need support as years go on because researchers are trying to detect the warning signs of ASD even earlier than they are currently able. This earlier intervention would help to ensure that the IDEA mandates on intervention can be put into place as soon as possible, and thereby increase the effects of remediation and increase the chances of improvement on their deficits (Sheldon & Rush, 2001). Another change that these mandates have also initiated is an increased focus on the environment in which therapy and early intervention services are provided. The mandates focus on keeping the child with disabilities in a natural environment when receiving services. Natural, indicating an environment familiar to the child such as their home or daycare opposed to a clinical office (Sheldon & Rush, 2001). This environment issue is especially important for children with ASD because becoming familiar and comfortable with environments is

a struggle for them, so placing them where they feel safe and familiar is most beneficial to their success.

Another regulation that has been influential to the evolution of ASD is the Charter of Rights of Persons with ASD. It was adopted as a written declaration by the European Parliament in 1996 (Feinstein, 2010). The Charter of Rights of Persons with ASD was developed to truly stipulate rights and regulations, which had not been clearly specified before for people with ASD. The European Parliament became pioneers and advocates for ASD because they believed that ASD was different from other disabilities making it necessary for people with ASD to have their own system of regulations. The reason for this position is because the disability itself requires a specific guideline as to the specific needs and issues of a person with ASD and what services they would require legally in order to live healthy and productive lives. This Charter was developed in order to have some sort of standard of care for people with ASD and also some standard of care by which an assessment could measure the quality and efficiency of services for people with ASD. This type of regulation helped not only the European sector, but also the United States as they also agreed to model their legislation to fit the Charter's requirements. The proposed charter below is the basis on which all legislation was modeled.

The Charter of Rights for Autism

1. The right of people with autism to live independent and full lives to the limit of their potential;
2. The right of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment;
3. The right of people with autism to accessible and appropriate education;
4. The right of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected;
5. The right of people with autism to accessible and suitable housing;

6. The right of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence;
7. The right of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life;
8. The right of people with autism to participate, as far as possible, in the development and management of services provided for their well-being;
9. The right of people with autism to appropriate counseling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken;
10. The right of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual;
11. The right of people with autism to accessible transport and freedom of movement;
12. The right of people with autism to participate in and benefit from culture, entertainment, recreation and sport;
13. The right of people with autism to equal access of all facilities, services and activities in the community;
14. The right of people with autism to sexual and other relationships, including marriage, without exploitation or coercion;
15. The right of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights;
16. The right of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution;
17. The right of people with autism to freedom from abusive physical treatment or neglect;
18. The right of people with autism to freedom from pharmacological abuse or misuse;
19. The right of access of people with autism (and their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records. (Charter of Rights, 1996)

The Charter of Rights is the foundation for the process by which people with ASD are to be viewed with the same lens as all other citizens in all countries. May 9, 1996 will be remembered by parents, professionals and friends of people with ASD, as a historic landmark in European society and the day that the rights were declared for people with ASD. The Declaration states that people with ASD should have the same rights enjoyed

by all citizens, which are in the best interest of the people with ASD and therefore will be upheld by each state (Williams, 1985). On this day, this Charter gained worldwide support because all nations agreed to use this as the standard by which people with ASD would be treated and services and rights would be developed.

From regulations that have been created and expectations that have been developed, the lives of people with ASD have been improved and changed. Another example of this is when another Pioneer, President George W. Bush enacted a policy in conjunction with the United States Congress which created the Executive Order on Community Based Alternative Treatment. This order also includes the Olmstead Decision. The Olmstead Decision was developed from a legal case, and its ruling which discussed community based needs of people with disabilities. The Olmstead Decision is based on a court case decision that was filed regarding the inappropriate treatment of two women Lois Curtis and Elaine Wilson, who had mental illness and developmental disabilities (*Olmstead v. L.C.*, 1999). These two women were patients in a psychiatric unit in the state-run Georgia Regional Hospital. When their treatment ended, they were ready to take part in community-based programs. However, the women were ordered to stay in the institution in which they had originally been placed. It was not until they filed a suit in conjunction with the provisions of the Americans with Disabilities Act (ADA) that this issue gained recognition and they were approved to leave the institution (*Olmstead v. L.C.*, 1999). Once the suit reached the Supreme Court, the decision was made on June 22, 1999, that segregation of people with disabilities is in direct violation

of the provisions of ADA and therefore discriminated against people with disabilities.

From this decision, came the Olmstead Decision (see Appendix B).

The rationale behind the importance of the litigation regarding community based services and treatments is that people with disabilities, especially people with ASD, thrive on being placed in natural environments in order to acquire life-skills which enhance their lives and improve their independence. Therefore, being institutionalized is less beneficial for a person who mentally can be independent. The court decision declared that it is unlawful for people with disabilities to be kept institutionalized if they are fully able to take part in community life skills. The decision also suggested that if these people are unlawfully kept in these facilities, it can harm their growth socially and emotionally. These are two areas which are already severely diminished in people with ASD. The court deemed the institutionalizing to be highly detrimental to their growth and existence in society. From this decision has come the opportunity for people with ASD to live productively in the community, and to develop lifelong independent skills instead of becoming institutionalized and never leading lives that are independent and self-sufficient, as other people are able to do freely and willingly. This decision once again, promotes the improvement in the quality of life for people with ASD and ensures a major improvement for those members of this population.

The most recent regulation put into place for people with ASD is the No Child Left Behind Act of 2001 that was put into place again by George W. Bush. This regulation was created to ensure that the education of all children would be developed

under a standard and assessed based on that standard, so that a certain quality of education was created from a federal level (Reville, 2007). All schools receiving federal funding were required to ensure that all students would be educated equally and not educated based on any other factor such as school or socioeconomic status or disability, but only by the standard set according to this act. If a school should fail to abide by the standards set and the assessments used to measure a school's performance are not met as per NCLB regulations, a school would be placed on a remediation plan (Linn, Baker, & Betebenner, 2002). Although NCLB was supposed to assist all students, including students with disabilities, it created a large issue for people with disabilities. The issue it created was due to the fact that regardless of the standard of education set, if the assessment to measure progress of student achievement is not adapted to consider the student's disability, it is not an accurate measure of the child's ability level. Because of this, NCLB was not a true help to people with disabilities, and did not fully assist students with ASD. In fact, depending on the population asked, one may say that NCLB has hindered progress with students with ASD because it has actually highlighted the inadequacies of these children by measuring them using the same standardized measure as used with their regular education peers (Linn et al., 2002). NCLB is in the process of being reauthorized and possibly amended, and the hope is that it will be revised to accurately consider those children with disabilities, specifically for children with ASD. However, no development has been discussed on this issue thus far.

All of the above regulations have had an impact on people with ASD. Some regulations have had a positive impact, but some not as positive as had been hoped.

However, all have enhanced the focus on students with ASD, which in turn, has been a positive influence on the evolution of the disorder because the more focus and knowledge concerning the needs of people with ASD the more services, treatments and independence that are created. Hopefully in the future, regulations will continue to improve the lives of people with ASD because with increased regulation comes increased awareness and increased rights.

Pioneers of Rights

From the regulations that are discussed in Chapter VI also came an increase in the rights of individuals with ASD. Regulations allow for legislation to be created and they also help mandate appropriate care and rights of those with disabilities. Some of the major events that defined an increase in the rights of individuals with ASD are events such as the World Health Organization officially recognizing ASD and publishing ASD in the International Statistical Classification of Diseases and Related Health Problems (ICD-9), the world's first Asperger's Syndrome Conference in London, the Supreme Court requiring states to provide community based treatments for people with disabilities under ADA, the ASD rights movement led by Jim Sinclair, and the United Nations declaring April 2nd World Autism Awareness Day with the United States adopting this declaration as well.

One major event that created awareness for ASD and that improved ASD rights and recognition was the first Asperger's Syndrome Conference in London in 1988 (Feinstein, 2010). Not only was this event meaningful for ASD, but it also was what sparked ASD being published in the ICD-9. Due to the conference, the need for a better

diagnosis was established because discussions about the diagnosis of Asperger's at the conference helped to better define the diagnosis. From the conference, two pioneers Christopher Gillberg and Peter Szatmari, developed standards of diagnosis which ultimately led to the publication in the ICD-10 in 1991 (Gillberg & Gillberg, 1989).

The next major change in the rights for ASD that is discussed in Chapter VI is when the World Health Organization became a pioneer for people with ASD. The World Health Organization recognized ASD, and therefore, it was published in the International Statistical Classification of Diseases and Related Health Problems (ICD-9) in 1979 (Kramer, Sartorius, Jablensky, & Gulbinat, 1979). The ICD-9 is an appendix defining individual categories of mental disorders. ASD being added to the ICD-9 meant it was now one step closer to more defined criteria of diagnosis for ASD. Prior to this identification, ASD was related as a sub-category of schizophrenia (Feinstein, 2010).

When the ICD-9 increased their criteria, so did the Diagnostic and Statistical Manual III. This was major progress because the more criteria added to the definition, the more accurate diagnosis became. From this point on, more and more diagnostic tools were created to determine what was, and was not considered ASD. In 1991, Asperger's syndrome which was considered a sub-category of ASD was then recognized as having its own diagnostic criteria by being published in the ICD-10, which was a revision of the ICD-9. This revision took place as a direct result of the translation of Han's Asperger's 1944 paper discussing the diagnostic criteria of Asperger's syndrome (Feinstein, 2010). Again, this was another immense gain for ASD because it demonstrated that not only was ASD being more commonly recognized, but so were its many sub-categories, which

meant that the more criteria developed to distinguish between these sub-categories the more specified treatments and services people with ASD can receive (Feinstein, 2010).

Instead of having treatment for people with disabilities with more well-defined criteria of diagnosis, the more defined treatments to address the characteristics of ASD can be developed. Though these developments in diagnosis occurred, ASD advocates insisted that there was much more to be done because the sub-categories such as Asperger's Syndrome were being misrepresented due to lack of knowledge and lack of awareness. However, the advocates did admit that the little gains in recognition meant that there were larger gains to be had in the future (Feinstein, 2010). No determination of classifying characteristics is ever perfect, so definite further improvements and simplifications will become a goal with the increases in knowledge of ASD and as more classification criteria accumulate over time (Jablensky, Sartorius, Hirschfeld & Pardes, 1983).

The next important event that helped influence growth with ASD was the Autism Rights Movement. This movement began in order to give rights to people with ASD, not as people with disabilities, but as people with differences. It is a movement that teaches people with ASD to be accepting of their disability instead of trying to masking it (Saner, 2007). The premise of the movement has empowered many people with ASD over the years, and the pioneers of this movement are ASD activists. One in particular known for his support of this movement is Jim Sinclair. Sinclair (1993) was the first activist to speak in favor of the anti-cure movement in the late 1980's. He was also known for his work with Autism Network International (ANI).

ANI is an organization in which the want for people with ASD to be neurotypical is not shared as the best treatment for people with ASD. Instead, the Autism Movement focuses on making people with ASD become more comfortable in their own skin by creating opportunities for them to be themselves instead of constantly developing treatments that try to remediate their autistic behaviors (Sinclair, 2005). This perspective of not curing ASD is controversial, but definitely demystifies the disorder by highlighting how when around a group of their own ASD peers, people with ASD are just that, people (Woodford, 2006). People with ASD may even be viewed as embracing their issues as theirs and not wanting neurotypical people to make them more normal (Sinclair, 1993). Some advocates and anti-cure activists view curing ASD as eradicating it or making sure the ASD does not exist, to which some take offense. Altogether, the Autism Movement has created awareness. Whether they are negative or positive views about the movement itself, Sinclair and the premise of the movement have added yet another dimension to ASD that makes it individual and enhances the influence it has on the evolution of ASD itself.

The last event that gained people with ASD more rights due to the awareness that it provided was the United Nations declaring April 2nd World Autism Awareness Day. In 2008, the United Nations became a pioneer for the face of ASD by declaring April 2nd World Autism Awareness Day. This was momentous for people with ASD because not only did it once again declare that they were their own separate entity from other disabilities, but it also declared one specific day to make gains in ASD awareness. On this day, so many parts of the country come together as one to advance ASD and heighten

discussion and celebration of ASD. Each area of the world celebrates the day in their own designated way, but some of those areas celebrate by raising flags, holding conferences, arranging celebrity performances, creating television commercials advertising it and much more. No matter how the day is celebrated, the important aspect is that ASD advances a little more each year concerning how people view and support ASD (Autism Speaks Inc., 2009).

Pioneers of Funding

With these regulations and rights declared, funding over time for ASD has needed to be increased. The increased needs of individuals with ASD created the need for better programming and increased services. Funding is the only way that these rights and services can be upheld as well as promoting an increase in the ability to continue research for ASD (Feinstein, 2010). Funding is one of the most important keys to progress for ASD, yet one of the areas that is lacking in positive results. ASD advocates have stressed for years that the ASD rates were increasing from year to year to the point of epidemic, but it was not until the late 1990's that notice was taken, and funding for ASD began to increase. Funds began being specifically allocated for several different areas of ASD research and exploration. Some examples of the funding increases recorded from 1980-2013 are in the late 1990's, the National Institutes of Health (NIH) contributed \$5 million dollars toward autism research, the Combating Autism Act of 2006 granted 950 million dollars in expenditures over five years to ASD in the areas of care and research, and President Obama pledged during his campaign of 2008 to commit \$1 billion dollars of

annual federal spending for ASD by 2012 because he identified ASD as one of his administration's top three public health priorities.

Originally ASD was not as individually recognized for funding as it is today. Over the past ten years, ASD has become more recognized due to its prevalence and because of the epidemic-like qualities that it has exhibited. Though ASD advocates believe ASD could benefit from more funding, funding has increased dramatically from the 1990's to the 2000's (Rehman, 2009). The National Institutes of Health (NIH) in the late 1990's funded roughly about five million to ASD research. This benefited the area of ASD specifically, which in past history was not available. However, it was necessary for research purposes to acquire much more (Rehman, 2009). By 2006, via the Combatting Autism Act, funding for ASD research had increased in dramatic fashion to a figure of 950 million over a five year period. Many ASD advocates feel that this funding was catapulted by the increase in ASD diagnoses during this time period. However, many also attribute the increase in funding to their efforts in creating awareness of ASD (Altevogt, Hanson, & Leshner, 2008).

The Combating Autism Act, Pub. Law No. 109-416 was enacted in 2006 by President George W. Bush for 950 million dollars over a five-year period. It was then revised in 2011 by President Barack Obama. This action extended the funding of 693 million from 2012-2014. This funding was designated to improve or address ASD issues in the areas of research, education, transition, treatment and services and/or early intervention (Altevogt et al., 2008).

The governmental mandates of the Act were created to designate parameters of the funding regarding specific areas of research for the treatment, causation and cure of ASD. Many advocates were hopeful that this funding was meant to alleviate the struggle of most parents of children with ASD who are constantly hopeful and looking for more research to be completed whether it be for information toward the cause of ASD or the cure for ASD (Altevogt et al., 2008). The government hoped that by putting this Act into place it would direct specific funding to specific areas. A few of the specific areas where funds were allocated were to develop a better understanding of environmental and biomedical involvement. One of the most important areas that the Act's funding was designated for was the area of early intervention. It was hoped that this early intervention study would include determining a better means of diagnosis via screening, as well as, programs for therapeutic intervention, which would then be better developed to serve children who were diagnosed with ASD (Rehman, 2009).

Through the efforts of ASD advocates, United States political figures, along with the advocates, have become the pioneers for the funding increase for this time period. Together, they are paving the way for new and improved research, interventions and diagnostic tools to be brought to light. These efforts should help all people with ASD live healthier and more productive lives.

Pioneers of Societal Acceptance/Celebrity Influence

With more regulations and rights being developed to govern the treatment for individuals with ASD and to ensure the treatment and education of people with ASD, a greater social acceptance of ASD has occurred (Feinstein, 2010). This acceptance was

especially notable during the period from 1980-2013. Celebrities played a very important role in this acceptance. Examples of this celebrity influence included Sylvester Stallone, Tommy Hilfiger and Jenny McCarthy are some of the celebrities who have become very well-known for helping bring acceptance of ASD to American society through their discussions about their loved ones' struggle with ASD. In addition, the movie *Rain Man* proved to be a major turning point for societal acceptance of ASD.

Due to the increase in celebrity discussions regarding ASD, an increase in awareness became evident in American society. This awareness has drawn interest in ASD, but it has also called people to action to provide increased services and research for those who struggle with ASD.

The realization in today's culture is that celebrity influence plays a major part of how society acquires current knowledge and awareness regarding major life issues (Bush, Martin, & Bush, 2004). An example of this is when ASD was first brought to the forefront of society by the movie *Rain Man*. *Rain Man* was a movie that premiered in 1988 starring two very famous actors, Dustin Hoffman who played Raymond, a man with autism, and Charlie, his brother, who was played by Tom Cruise. The stars alone intrigued people to watch and become involved in what the movie was about, and because it was well received, people who viewed the movie began speaking about ASD. People wondered what the disorder was and how people acquired it. The movie was discussed on the news, talk shows and magazines. The negative side of this publicity was the somewhat skewed nature in which ASD was portrayed. Raymond was known for his

anti-social or socially awkward demeanor, as well as, his amazing memory and savant-like skills (Treffert, 2009).

Though this was a very important time for the ASD world, this increased attention for ASD had both negative and positive effects concerning the recognition of the disorder. The positive effects and societal influences the publicity of the movie had on ASD, catapulted the knowledge of the disorder to the center of attention (Treffert, 2009). The fact that no disorder other than ASD at the time, had received such widespread notice from a movie was viewed as a positive aspect. In the movie's initial opening at the box office, ASD advocates mentioned that there had been no greater publicity for ASD. However, in that same breath, the movie also shed light on a very shallow description of this disorder (Treffert, 2009).

After the movie had premiered, for some time, people's opinions regarding its success was that it had portrayed all people with ASD in a way that lumped them together by suggesting that they all have a very high IQ, all are completely socially awkward and all people with ASD were savants (Peek, 1996). This was obviously not true, and was a somewhat difficult predicament because advocates of ASD loved that such publicity had come to light for ASD. People had not only taken notice of the disorder, but they were discussing it publicly and wanting to know and understand more. However, this increased awareness also made advocates question whether or not the true wonder was about ASD or the fame that the savant-like skills had drawn (Treffert, 1998). Either way, there is no denying the effects that the movie *Rain Man* had on the societal awareness

regarding ASD in 1988. This made the movie one of the most influential events in ASD history (Treffert, 2009).

Movies and media are not the only source of publicity ASD has received over the time period of 1980-2013. Celebrities' ability to heighten awareness regarding their family members with ASD has played a huge role in the awareness that has been drawn to ASD. Three top celebrities who have been noticed and who will be discussed in this chapter are Sylvester Stallone's son, Tommy Hilfiger's daughter and step-son and Jenny McCarthy's son. Together these top celebrities have opened new doors of awareness regarding ASD and the acceptance and influences that have been necessary for growth and research and funding developments for ASD.

Sylvester Stallone and Tommy Hilfiger are two very well-known celebrities who have made it their personal mission to increase research, funding and awareness in honor of their children who have ASD. Stallone through his acting and Hilfiger through his fashion empire, have both realized that if they can bring the kind of awareness to ASD as they can to movie premiers and fashion shows, then, ASD will be in the position to be recognized by political figures. It will also have an effect on the parents of people with ASD who will then feel more supported and have more of a chance to gain from further research and funding toward discovering a cure or assistance for their loved one.

Sylvester Stallone's son Seargeoh was diagnosed at the age of three with ASD. In the 1980's this was very significant for an actor to admit that his child had a mental handicap. Actors were often looked at as untouchable; especially Sylvester Stallone whose movie characters often represented very strong masculine personas. Stallone's

public announcement of his son's illness spoke volumes as to how involved he wanted to become in research efforts and funding for progress toward a cure and a better life for children with ASD (Trip, 1997). Stallone discussed his son's diagnosis in *People* magazine, which was a huge step in awareness and helped him begin his research fund that was funded under the National Society for Children and Adults with Autism (Zannos, 2000). In an interview Stallone stated,

"There is no real father-and-son thing there," he says. "I have to become his playmate. With a child like this you have to put away your ego. You can't force him into your world. I sort of go along with whatever he is doing. Sometimes he likes to draw, mostly abstract things, and he has puzzles that we work on together. After he gets to the point where he trusts you, a little more communication can start. The primary therapy is the repetition of words and instructions. He has shown an extraordinary memory, but he can't apply what he has learned." (Arrington, 1985, p. 43)

"To have a child in this predicament is extremely sad," he says. "It's almost like a radio station—he fades on and off of the signal." When Sly does see the boy ("a couple of times a week when I'm in town"), his major effort is to keep his son tuned in. "I have tried to build my yard into a New England playground environment, where Seargeoh can go outside and relate to nature and hear the flowing water. That seems to bring him out a little." (p. 43)

Stallone and his wife Sasha made it their personal mission to use their celebrity and opportunities, along with their money, to increase awareness and help fund new research. Just over a short time after the diagnosis, Stallone helped raise over a million dollars in research funds through his organization (Arrington, 1985). In 1990, Stallone also created a Public Service Announcement. This announcement was broadcast to help increase awareness for people who knew someone with ASD and Stallone encouraged these people to contact their local chapter of the Autism Society of America for more assistance with helping their loved ones with ASD. This type of public display of

awareness helps society find a purpose to understand this disorder. It also discusses the need for society to make it a priority to support, funding and educating the public regarding the needs of people with ASD (Trip, 1997).

If celebrities were to keep quiet about their personal struggles, it would be a huge disservice to the public because the care and awareness regarding ASD would be lessened. Tommy Hilfiger not only has a daughter named Kathleen who has ASD, but his wife Dee also has a son Alex with ASD as well. Hilfiger became involved with Autism Speaks Inc. to honor his daughter because he did not feel that enough was being done to raise money for research or to help support those caring for people with ASD. He and his wife agreed that if political figures are not going to take control of gaining further funding and research for ASD and place a high importance on the so-called epidemic, then, they would at least try to do their part by speaking out on behalf of ASD whenever they had the public's attention. Hilfiger also helped create a public service announcement in 2012, as part of the Learning the Signs campaign (Autism Speaks Inc., 2012). Hilfiger and his wife also both take active roles on the board of directors of Autism Speaks Inc., so that they can use their celebrity, as much as possible, to enhance the organization and help to raise money for its many ASD endeavors. Hilfiger stated in an interview he did in 2013 that, "One always prays for the day when they can be totally independent, but there's a question mark. We hope that Kathleen and Alex will grow up to be productive, healthy, happy. But we don't really know" (O'Neill, 2013). This statement signified to society that not even fame or fortune can bring security to someone whose children are

affected by ASD and because of this everyone needs to bond together to create awareness.

Jenny McCarthy is probably one of the most well-known celebrities for the face of ASD because of her son Evan who was diagnosed with ASD at the age of five. McCarthy first revealed her son's diagnosis in May of 2005. She also published a book documenting her struggles with her son's ASD in 2007. She then went on to speak on the Oprah Winfrey show in 2007, which notoriously sparked an exceptional amount of controversy because she discussed what she believed to be the cause of her son's ASD, which was vaccines (Alston, 2007). She also went on to state that she believed there was a cure or *healing* for ASD as she outlined in her books. The healing of ASD, which she speaks of in her book, which she co-wrote with Dr. Jerry Kartzinell. She described the struggle she went through regarding her son Evan's diagnosis as she said,

So, I hunted for the very best neurologist, someone who would give me insights into my unanswered questions. He took one look at Evan and said, "I'm sorry; your son has autism." "I died in that moment. All of my future images of Evan getting married or hugging me on his way to college broke into a million pieces. (McCarthy & Kartzinell, 2010, p. 2)

The controversial storm went on for years and still does, as people question which vaccinations how much and when vaccinations should be given. Society has mixed emotions regarding McCarthy because she has made so many people question their pediatricians, and some even have made the decision not to vaccinate based on her claims that ASD is caused by vaccinations (Ratledge, 2013). There are also many skeptics of her claims that there is a cure for ASD, which she writes as outlined in her book. She states, "Within a year of following Dr. Jerry's protocol and intensive

behavioral and speech therapies, Evan recovered from autism” (McCarthy & Kartzinel 2010, p. 3). Many ASD advocates claim her comments give false hope to parents who already feel defeated over their child’s diagnosis. Health experts also believe she has created new health concerns when it comes to vaccinations because she is potentially seen as having views which lean more towards omitting vaccinations, however she states she is an advocate for safe vaccinations not omitting vaccinations (Freeman, 2013).

Even though McCarthy may be viewed somewhat negatively, there is no denying that she has been a strong stakeholder in ASD awareness, as well as, research and discussions about ASD. Whether or not her information is seen as valid or declared invalid, her efforts to bring emphasis to aspects of ASD, have encouraged people to become more aware of the causation and treatment of ASD as well as becoming major influences toward the evolution of ASD.

What Does This Mean for Schools?

The main contribution for the pioneers in this chapter is parameters, awareness and funding. With the contributions of the pioneers in this chapter, schools have benefited from the funding that has gone into creating awareness and growth for ASD. All of the growth that has taken place has created the ability for schools to better educate students with ASD while also transitioning them for their lives after school.

The regulations, rights, funding and societal awareness that have been brought about by these pioneers has created a broader education for schools over the years and has made them more sensitive and aware of the needs of students with ASD.

Each area discussed has evolved from 1980-2013, along with the pioneers and advocates who have advanced this evolution has contributed to the growth, in treatment and services provided for people with ASD today. Influence in the areas of politics, legislation and celebrity are often times so powerful that the advancement brought forth by all of them are historical in nature and will forever have left an imprint on the definition of ASD and change how the school system treats and educates students with ASD. The pioneers' and advocates' in the areas of regulations, rights, funding and societal acceptance are people who care about ASD in one way or another and who have had a powerful influence in the ASD world. These pioneers do not have to agree nor do they have to have the same goals as long as their main focus is the growth in promoting services and in awareness toward ASD. If that is the main focus of all of the future pioneers and advocates, ASD will continue to evolve for the betterment of the people who live with it every day, and therefore, the focus will better define the role of schools as this evolution continues to take place.

CHAPTER VII

CONCLUSIONS AND SUMMARY

The purpose of this study is to examine the evolution of understanding of ASD from 1980-2013. Specifically, this study will identify (1) pioneers and advocates for change in the areas of medical diagnosis and treatment of ASD, (2) pioneers and advocates for change in assessments of ASD, (3) pioneers and advocates of change in therapies and educational treatments of ASD, and (4) pioneers and advocates of change in the regulations, rights, funding and societal acceptance of people with ASD. The methods of advocacy will be determined, as well as the impact of the advocated changes on those with ASD. Additionally, this study explored the implications for educational leaders as advocates for educational programming, societal acceptance, care and respect for people with ASD.

Research Questions

In order to examine the evolution of ASD and the roles that pioneers and advocates have played in the growth of awareness of ASD, this study answered the following research questions:

- 1a) During the time period from 1980-2013, who were the pioneers and advocates in the medical field for ASD?
- 1b) By what means did they advocate, and what role did their advocacy play in the evolution of diagnosis and medical treatment?
- 1c) How did the changes in the medical field impact those with ASD?

- 2a) During the time period from 1980-2013, who were the pioneers and advocates in assessment for ASD?
- 2b) By what means did they advocate, and what role did their advocacy play in the evolution of assessment?
- 2c) How did the changes in assessment impact those with ASD?
- 3a) During the time period from 1980-2013, who were the pioneers and advocates for therapies and educational treatments for ASD?
- 3b) By what means did they advocate, and what role did their advocacy play in the evolution of assessment?
- 3c) How did the changes in therapies and educational treatments impact those with ASD?
- 4a) During the time period from 1980- 2013, who were the advocates for increasing the regulations, rights, funding and societal acceptance of ASD?
- 4b) By what means did they advocate , and what role did their advocacy play in the evolution of increased regulations, rights, funding and societal acceptance?
- 4c) How did the changes in increased regulations, rights, funding and societal acceptance impact those with ASD?
- 5) What are the implications for today's educational leaders as advocates for educational programming, societal acceptance, care and respect for those with ASD?

1a) During the time period from 1980-2013, who were the pioneers and advocates in the medical field for ASD?

1b) By what means did they advocate, and what role did their advocacy play in the evolution of diagnosis and medical treatment?

1c) How did the changes in the medical field impact those with ASD?

The pioneers who were deemed influential in the medical field from 1980-2013 for this research study, were Leo Kanner, Hans Asperger, Lorna Wing, and Margaret Bauman. Each pioneer had his or her own influence in taking ASD from being referred to as a mental disability to a disability with a voice and meaning. Leo Kanner and Hans Asperger made it their personal mission to demonstrate that people diagnosed with ASD were not cognitively insignificant, but they were people with promise and would become active productive members of society. Both men believed that if society would keep an open mind and recognize the potential of these individuals' education, care and support would follow. From this belief and their works discussing the findings of their research studies involving children with ASD, they both highlighted the gains that the children were able to achieve when given the opportunity and support to do so.

Kanner (1943) contributed his separation of ASD from other psychoses and created his five diagnostic criteria that have been altered as progress has been made, but are still used today as a foundation for diagnosis. Kanner also brought to the forefront the discussion of ASD being caused by lack of parental involvement or it being innate. In the same regard, Asperger was responsible for the delineation of identifying behaviors for ASD as well as demonstrating that these behaviors could also be looked at as gifts

when placed in specific situations. These behaviors that he discovered were also used as markers for diagnosis as well, and Asperger urged further research be completed so that earlier diagnosis could be achieved. Lorna Wing carried on Asperger's mission by continuing this research until her recent death on June 6, 2014. Wing (1981) developed what began as a concern for research because of her daughter's diagnosis of ASD, and made her concern into a life-long endeavor to increase the knowledge and research regarding ASD. Wing believed that the more effective the diagnosis process became and the more information that was made available to parents, the better for the child with ASD, and the more productive their lives would become. Margaret Bauman felt the same regarding the need for a more qualified diagnostic process and improvements in determining causation. Her work regarding neurological markers became renowned for its enlightening insight regarding innate causation as opposed to parental insufficiencies. Bauman (1991) has helped to shed light on the need for a specific cause and made physicians and researchers broaden their lenses of diagnosis, in the hope that in the future physicians and researchers can identify these markers and lessen the impact or cure the disorder.

This research also contains discussions regarding some of the changes in the medical field during this time period that have added to the evolution of ASD. These discussions included the changes in the DSM information from the third edition to the fifth edition. Some of the differences between editions include the changes and influences of the DSM regarding terminology and diagnostic criteria of ASD, the definition of Pervasive Developmental Disorder (PDD), Autistic and Pervasive

Developmental Disorder Not Otherwise Specified (PDD-NOS), and the inclusion of the Asperger's Syndrome diagnosis, plus the most current exclusion of the diagnosis from the DSM. These items have all shaped the diagnosis itself and helped to determine how medical professionals as well as school professionals view the diagnosis and treat people who have been identified by this diagnosis. Though the inclusions and exclusions for the diagnosis in the DSM have changed and evolved, it has still made ASD relevant and helped to differentiate it from other diagnoses.

Several other causes have been linked to the diagnosis, and over time this will again change and evolve. However, during the time period of 1980-2013, the changes have really been wide ranging. The range includes classifying the diagnosis as one thought to be brought on by poor parenting, then, thought to be one caused by environmental toxins, then, to one regarding genetic components. The more the topic of causation is brought to the forefront, the greater the chance for controversies regarding the true cause to arise. People want answers, and because of this situation, they are heavily influenced by the slightest proof of cause. This situation is confirmed by the controversies discussed in this research. An example of such controversies would be the belief that a mother's inability to bond with her children had a profound effect on the child according to Andrew Wakefield and his findings regarding vaccinations. All of these different theories regarding causation have helped in the evolution of this diagnosis and have changed how people view ASD.

2a) During the time period from 1980-2013, who were the pioneers and advocates in assessment for ASD?

2b) By what means did they advocate, and what role did their advocacy play in the evolution of assessment?

2c) How did the changes in assessment impact those with ASD?

The pioneers who were deemed influential in the area of assessment from 1980-2013 for this research study, were Simon Baron-Cohen, who created the CHAT, Lorna Wing and Judith Gould, who created the DISCO formerly known as the HBS, and Eric Schopler and Robert Reichler, who created the CARS. Each of these pioneers and advocates has taken the area of assessment and developed tools and protocols that have advanced the diagnosis of ASD.

Simon Baron-Cohen's work regarding the theory of mind and mind blindness really helped to establish the diagnosis. This work helped professionals from all fields realize that ASD is not a diagnosis of psychosis, but one where the mind cannot understand that other people have opinions, beliefs and desires that may be different from their own. People with ASD have issues with this piece of social interaction and with a deficit in this area; it makes appropriate social communication very difficult. It was very important to have sound assessments developed in order to improve accuracy of diagnosis as well as uniformity among professionals. Baron-Cohen's work revolved around the belief that if professionals had a diagnostic tool to utilize early in a child's development, the instrument would assist them in taking note of these deficit areas, and diagnosis would not only be more helpful, but also more accurate and more decisive. This result would be due to the areas of development that could be monitored as a child grows. The CHAT was developed based on his beliefs in the areas of deficit and what he

thought would be the best and most effective way to diagnose. Although the CHAT was more of a screening tool, it also helped with diagnosis. It was able to help identify whether certain children are more at risk for developing autism depending on their current level of development. Then, from that screening result, a parent and physician could create a plan that would help the screened child receive support if needed and also qualify the child for further testing. This tool was developed to hopefully help diagnose children at a very early age. This would make it easier for children to receive treatment for their deficit areas earlier in their development.

Lorna Wing and Judith Gould are the creators of the DISCO which was formerly known as the HBS. These women had a similar goal as Baron-Cohen. They wanted to improve the diagnostic process in order to increase the effectiveness of treatment as well. They chose to create this assessment because of their overwhelming desire to create a diagnostic tool which was advanced and assessed more areas. At the time, there were no current tests which had diagnostic interviews available. The DISCO was created as a subset to the formerly created Handicap Behavior and Skills Schedule that Wing and Gould had originally created. The DISCO was then created or added because of Gould's and Wing's beliefs of the full spectrum of disabilities (Wing, 1981). Wing and Gould believed that there was such a strong link between the commonalities of the lack of social communication and the interaction of ASD, that a diagnostic test which revealed these deficits would eventually give the diagnostician as well as other professionals a bigger picture of existing social deficits. Like Baron-Cohen, their goal to achieve a sound

diagnostic tool was extremely necessary to give more information to parents at the most serious time in their children's lives.

Schopler and Reichler were also discussed in this research for their work creating the CARS. This is in addition to their drive to also support furthering the research in the area of diagnosis. Schopler and Reichler wanted an assessment they believed would lead parents and diagnosticians to a clear diagnosis for the child. Though the CARS was intervention based, the two men believed that the more accurate their assessment was, the more it would lead to a better source of therapeutic intervention based on the clear cut diagnosis. The CARS assessment was developed to define and diagnose each individual as the individual's characteristics related to ASD. Although there were other assessments being considered, this assessment was felt to give a more individualized diagnosis and would hopefully result in a more individualized treatment plan for the child.

The effects these assessments had on schools and the increase in diagnosis was significant because the earlier and more accurate the diagnosis, the better the opportunity for successful treatment and the earlier school support can be applied. Of course, once better assessments have been created, the increase in the ability to identify the disability may increase resulting in a larger influx of the number diagnosed. However, with a larger influx in diagnosis also comes more knowledge of the disability and hopefully better treatment and support. Early Intervention is an important example of these opportunities for support. Due to the assistance of these assessments, parents can better ensure that their children are provided the best educational provisions possible based on their child's individual needs and diagnosis.

3a) During the time period from 1980-2013, who were the pioneers and advocates for therapies and educational treatments for ASD?

3b) By what means did they advocate, and what role did their advocacy play in the evolution of therapies and educational treatments for ASD?

3c) How did the changes in therapies and educational treatments impact those with ASD?

The pioneers who were deemed influential in the area of therapies and educational treatments from 1980-2013 for this research study were Ole Ivar Lovaas (creator of the Lovaas method), Eric Schopler (creator of the TEACCH program), Carol Gray (creator of Social Stories), Michelle Garcia Winner (coined the term social thinking and developed educational therapy tools revolving around the concept of social thinking), and Kalle Reichelt (creator of the Gluten and Casein Free Diet). These pioneers each have a vested interest in the therapeutic intervention of people with ASD.

Dr. Ole Ivar Lovaas pioneered the Lovaas method and is now recognized as one of the first people to realize that behaviors related to ASD could be changed or modified through treatment and not just masked. Lovaas's is responsible for research on ABA. ABA was known in its early stages as behavior modification. Lovaas aspired to find a therapeutic treatment that helped people with ASD to not only modify the behavior, but identify the root of what caused the person with ASD to have these behaviors. His Lovaas method is a treatment plan that begins when the child is very young and continues in order to transfer the plan into the child's everyday life. What differentiates his treatments from others is the Discrete Trial Training (DTT) that is incorporated into the therapy.

The use of DTT was believed by Lovaas to be the most effective treatment methods because of the routine beginning and end in the method. He believed a child with ASD needed this method in order to be able to predict the outcomes of his actions and the actions of those around him. His treatment was based on a belief system including, positive interactions, motivation, success and parental involvement combined with learning to request items, language improvement, imitation plus social interaction and cooperative play. These are all areas that Lovaas believed to be important for behavior therapy and are completed with the child through one-on-one guidance. Lovaas's intensive model is well-known among his peers. It has been deemed evidence based and has had numerous research studies conducted on its efficacy. The model also employs a scaffolding process to ensure the carryover for the child into school and other environments.

Eric Schopler, was chosen because of his work not only with the CARS assessment, but also as the founder of the TEACCH foundation and program. His work with TEACCH caused him to research and develop a treatment structured around his beliefs that ASD is a developmental disability and not a psychosis as it had once been described. TEACCH is a program that believes that the parental role in treatment is important, and incorporating parents into treatment has immense benefit to treatment success. It is based on the *autism culture* which means the program is not looking to change the person with ASD, but help them to function more efficiently in their daily lives. It is also combined with structured teaching. The main goal of the program is to help those with ASD to have easier and more productive lives by decreasing their less

preferable social behaviors. It is also based on visual learning, which helps because it is structured.

Carol Gray was chosen as a pioneer because of her work on the creation of Social Stories. Because deficits in social interaction and the understanding of pragmatic language are the main deficit areas of people with ASD, social stories have been a staple in therapeutic treatment. The method takes real-life occurrences and breaks them into a story-like format for the person with ASD. This process helps to define what actually happened during the event, and it allows the person with ASD to take ownership of retelling the story in a structured manner. This procedure seeks to explain the event in a manner the person can understand. Carol Gray developed a specific format for social stories that is systematic in nature. It can be utilized by all professionals in the same manner across many disciplines. This ensures that there are not mistakes in the usage or outcome of the therapy tool. The sentence formats are descriptive sentences, perspective sentences, directive sentences and affirmative sentences. The goal is not to use as many directive sentences in the formatting, so the student stays engaged and does not only see directives and does not miss the social and environmental cue information. With the use of this therapy tool, the formatting and structure helps the student realize how his behavior affects others.

Michelle Garcia-Winner was chosen as a pioneer because of her work developing the therapy treatment of social thinking. She created therapy tools based on her experience with people with ASD as a Speech-Language Pathologist. She created the term social thinking. It is now used by many professionals to describe a therapy

technique that helps people with ASD begin to think like their conversational partners and develop the skills of social interaction. Michelle's main goal was to ensure that these therapy strategies are easy enough for parents, teachers and therapists to use, and to develop practical adaptations for these clients to use in their everyday lives. Again, Michelle, like the other pioneers, had a desire to develop a therapeutic intervention that would carry over into the real life environment, and eventually help people with ASD to lead more productive and social lives. ASD is a very self-oriented disorder, so neglecting the conversational partners is very typical, but social thinking was created to help remediate this issue. There are 12 core points of social thinking, and Michelle does her best to incorporate these into her therapy materials. Each therapy tool is based on social development and interaction. Decreasing socially inappropriate behavior and social thinking is taught and used to encourage social interaction within a conversation. The 12 core points take the information we know as socialized individuals and teaches it to people with ASD with social deficits.

Garcia-Winner is also famous for speaking about the "hidden curriculum" within our social language. Because people with ASD are missing the decoding tools they need to understand this hidden curriculum, conversational breakdowns occur. Garcia-Winner's therapy tools teach the decoding tools that people with ASD need to think about other peoples' thoughts, feelings and emotions. It soon becomes a natural action for them to use during social interaction. The last pioneer mentioned in the evolution of treatments over this time period is Karl Ludvig Reichelt also known as Kalle Reichelt. He is best known for his development of the gluten and casein free diet as a treatment for

people with ASD. He discovered what was believed to be a link to the consumption of gluten and casein and the traits of ASD. Trying to alter diets to cure different ailments was not a new phenomenon among researchers and scientists alike. However, when Reichelt's diet theories came about, it was at a time when little was being done for people with ASD, and parents and doctors were trying new trends to find something that would assist in improving behaviors of ASD. Though Reichelt's claims are said to be controversial, there are many people who still claim the diet helps their children and they still faithfully remove these two items in order to help children with ASD. Due to this apprehension in participation in studies using the diet, there is not a lot of evidence for the efficacy of the diet. However, this diet still made a marked impression on the ASD map of therapeutic interventions, and it definitely helped in the evolution of the different types of tools that are deemed therapeutic in nature for assisting with ASD.

The effects that these therapies and educational treatments have had on ASD over the years have been remarkable for ASD. These therapies and treatments can all happen within the school setting, not to mention that having this variety of therapeutic techniques to try and help people with ASD shows how much ASD treatment has evolved over time. The more people are trying to improve the skill level of people with ASD, the more productive their lives will become. Often times these kinds of treatments are worked into a child's IEP and need to be implemented legally. Therapy treatments for ASD have changed and progressed over time. However, the main aspect that they have all encompassed is the need to help people with ASD live more productive and socially capable lives.

4a) During the time period from 1980- 2013, who were the advocates for increasing the regulations, rights, funding and societal acceptance of ASD?

4b) By what means did they advocate, and what role did their advocacy play in the evolution of increased regulations, rights, funding and societal acceptance?

4c) How did the changes in increased regulations, rights, funding and societal acceptance impact those with ASD?

There were several pioneers who were deemed influential in 1980-2013 for this research study in the areas of regulations, rights, funding, and societal acceptance.

Pioneers of Regulation

The United States Congress was a pioneer itself when it mandated the Education for all Handicapped Children Act (EHA), which is now called Individuals with Disabilities Education Act (IDEA). Bill Clinton was a pioneer during this time because while he was in office, IDEA was amended. This amendment included even more mandates for better support services for people with disabilities, which of course included ASD (*Individuals with Disabilities Education Reauthorization Act*, 2004). With these additions, ASD was added as a category for reporting statistics to the United States concerning the utilization of special services within the schools. This action made a huge impact on ASD because Early Intervention services were added as part of the amendment. This action meant earlier services could be received to help remediate some of the early deficit areas (Epley, Summers & Turnbull, 2011). Also, this allowed the opportunity for these services to occur in the child's natural environment for easier carryover.

The European Parliament was recognized for being a pioneer and advocate for ASD because of their belief that people with ASD deserved their own Charter of Rights which was enacted in 1997 and gave people with ASD their voice (Eply, Summers & Turnbull). They believed this because there are specific needs that should be delineated when working with people with ASD, and these delineations help make the outside support and treatments clearer and more regulated for them. The Charter was developed to set a standard of care for people with ASD. This standard carried over into the United States, and there began to be a more standard order of mandates created for people with ASD in the United States as well.

George W. Bush is also viewed as a pioneer during this time because of his development of the Executive Order on Community Based Alternative Treatment, which also includes *Olmstead v. L.C.* *Olmstead v. L.C.* was a legal case ruling that community based treatment should be mandated and regulated to meet the needs of people with disabilities. These legal regulations not only made community based treatments mandatory, but they also stated that the people receiving these treatments be given accommodations as needed (*Olmstead v L.C.*, 1999). Again, the rationale for this type of treatment as a necessity for people with ASD is based on the fact that people with ASD thrive when treatment is given in their natural environment. Therefore, community-based programming is one of the keys to successful daily lives for people with ASD.

No Child Left Behind Act of 2001 was also developed by George W. Bush to ensure that the education of all children would be developed with some sort of standardization. President Bush mandated that in order for schools to receive Federal

funding, these mandates had to be followed potentially ensuring that children with ASD would have improved standards of education. Though this regulation came about with good intentions for people with disabilities as well as people without, the results may not have been as effective as the designers had hoped. Though NCLB was not received from people with ASD as well as it could have, it still had part in the evolution of the disorder by highlighting how specific standards truly need to be regulated based on the needs of people with disabilities and not just by a standardized process for all schools.

All of the above regulations have had an impact on people with ASD. Some have had a positive effect and some have not, but all have provided focus on ASD as a whole. These regulations have helped ASD to evolve into what the diagnosis is and receives as benefits and supports today.

Pioneers of Rights

One major event that created awareness for ASD and that improved ASD rights and recognition was the first Asperger's Syndrome Conference in London in 1988. Not only was this event meaningful for ASD, but it also was what sparked ASD being published in the International Statistical Classification of Diseases and Related Health Problems-9 (ICD-9). Due to the conference, the need for a better diagnosis was established because discussions about the diagnosis of Asperger's at the conference helped to better define the diagnosis. From the conference, two pioneers, Christopher Gillberg and Peter Szatmari, developed standards for diagnosis.

The next major pioneer in the rights for ASD was the World Health Organization. The organization was deemed a pioneer for people with ASD because they recognized

ASD, and this resulted in it being published in the International Statistical Classification of Diseases and Related Health Problems (ICD-9) in 1979. ASD being added to the ICD-9 meant it was now one step closer to more defined criteria of diagnosis for ASD. When the ICD-9 increased their criteria, so did the DSM-III. So many changes occurred with the terms of diagnosis and also affected the DSM. These changes then impacted people with ASD positively because the more clarity involving the terms for diagnosis, the better the process becomes. In addition, more people would be identified to receive treatments they need in order to have success in their lives.

Sinclair was another pioneer who is best known for his support of the Autism Rights Movement. This movement began in order to give rights to people with ASD, not as people with disabilities, but as people with differences. Jim Sinclair was the first activist to speak in favor of the *anti-cure* movement in the late 1980's. He was also known for his work with Autism Network International (ANI). This is an organization which does not advocate for people with ASD to be identified as neurotypical as the best treatment for people with ASD. Instead, the Autism Movement focuses on making people with ASD become more comfortable with their disability. Having the Autism Movement created awareness as well as a bond between people through a common cause which helped create a broader knowledge base that has had a positive impact on the evolution of ASD.

The last pioneer for the rights of individuals with ASD was the United Nations and their declaration of April 2nd as World Autism Awareness Day. In 2008, the United Nations became a pioneer for the face of ASD by declaring April 2nd World Autism

Awareness Day. This was momentous for people with ASD because not only did it once again declare that they were their own separate entity from other disabilities, but it also declared one specific day to make gains in ASD awareness. This day has affected all parts of the world. The increase in awareness and recognition of the disability has definitely shown that ASD has evolved from a disability in which people were thought to be in need of institutionalization, but now are given an identity and sense of approval.

Pioneers of Funding

Again, President George W. Bush was a pioneer regarding funding for ASD because he enacted The Combating Autism Act, Pub. Law No. 109-416. In 2006, funding was enacted by President Bush for 950 million dollars over a five-year period for ASD research. The National Institutes of Health (NIH) in the late 1990's funded roughly about five million for ASD research. This funding benefited the area of ASD specifically, for which funding was not previously available. The Combating Autism Act increased funding for ASD research. This increase helped in the evolution of ASD because the increased awareness regarding ASD, due to funding, helped bring about more research, which was needed as the rate of diagnosis increased rapidly (Combating Autism Act, 2006). It was then revised in 2011 by President Barack Obama who became a pioneer for his extension of the funding to 693 million from 2012-2014 (Combating Autism Reauthorization Act, 2011). This funding was designated to improve or address ASD issues specifically (Combating Autism Reauthorization Act).

Pioneers in Societal Acceptance/Celebrity Influence

An increase in societal acceptance could be especially noticed during the period from 1980-2013. Celebrities played a very important role in being pioneers because their influence on society has also shaped the diagnosis of ASD. Sylvester Stallone, Tommy Hilfiger and Jenny McCarthy are some of the celebrities who have become very well-known for helping bring acceptance of ASD to American society through their discussions about their loved ones' struggle with ASD. In addition, the movie Rain Man proved to be a major turning point for societal acceptance of ASD.

Rain Man was a movie that premiered in 1988 starring two very famous actors, Dustin Hoffman. Hoffman, played Raymond, a man with autism, and Tom Cruise played Charlie, his brother. The topic as well as the fame of the actors helped immensely by making ASD the center of attention. Though the movie had a very narrow view of ASD, the attention it gained began the discussion of ASD in the public.

Celebrities have the same ability to heighten awareness by being candid about discussing the struggles of their loved ones who have ASD. Sylvester Stallone's son, Tommy Hilfiger's daughter and step-son and Jenny McCarthy's son all gained media attention from their fans and other members of society alike. Together, these top celebrities have opened new doors to awareness regarding ASD. Their experiences have increased the acceptance and influences that have been necessary for growth in research and increased funding developments for ASD. Their philanthropy and drive to share their personal experiences with people they love having ASD has really given ASD a voice in the manner that society now knows it is more than just a mental disorder. Their

experiences demonstrated that even people with status have been touched by ASD in some manner. In today's world with such increased public/media interest, having celebrities be open and honest about their experiences involving ASD can be worth so much more than any physician or research expert can provide.

5) What are the implications for today's educational leaders as advocates for educational programming, societal acceptance, care and respect for those with ASD?

In this research study, the implications for today's educational leaders are vast and extremely important as they, as leaders, need to become pioneers and advocates for their students with ASD. Today's educational leaders have the ability to enhance the educational programming, societal acceptance, plus care and respect for those with ASD. The following information discusses how, with the knowledge gained from this study, these educational leaders can execute this process most effectively:

1. Today's educational leaders need to be conscious of events in the medical field and the direction research is headed in relation to ASD. As an educational leader, the responsibility of being well versed in the process of diagnosis as well as what an actual diagnosis for ASD entails is critical for the identification of students with ASD. It can also impact the students' level of success in the classroom. Knowing the background of how ASD has evolved can also be beneficial because the diagnosis itself has evolved from 1980-2013, and it will continue to evolve with further research being conducted in the areas of diagnostic tool development plus further study regarding causation and student needs. Today's educational leaders need to understand

the assessments that are available for their staff to use in order to provide parents and other educators with the best information concerning how to educate students with ASD most effectively. Often times, students with ASD receive a medical diagnosis, but educational staff such as a school psychologist, speech pathologist and other therapy related support staff conduct assessments to determine the best way to assist in educating students with ASD. It is for this reason that today's educational leaders should know the process of assessment. They also need to know the assessments that their school district utilizes to ensure that these instruments are the most effective in providing appropriate services for their given ASD population. By acquiring knowledge regarding the assessment process, the educational leader can provide support that will be beneficial to the staff and students. They can also make the IEP process more individualized for each student during goal development and educational planning. This knowledge base can help to reassure the parents that the school is well versed in the needs of their child and how those needs are going to be addressed.

2. Today's educational leaders need to know the latest and most effective therapies and educational treatments that are available for students with ASD. This knowledge has the potential to make education within the classroom as well and related services for students with ASD more effective. It can also be more cost effective to stay current with the latest and most effective therapies and educational treatments. In this way, time and money are not wasted

searching and utilizing techniques that will not produce the most effective outcome for students with ASD during their time in school and for their post-secondary endeavors.

3. Today's educational leaders need to be aware of the regulations, rights and funding that people with ASD require and deserve. If this knowledge is acquired by the educational leader, the students with ASD will gain the most benefit from the funding and support that has been granted to them by law. Knowing the legal aspects of ASD as well as the support services that are rightfully theirs can make educating these students more effective and more comprehensive. Acquiring this knowledge will also help decrease any adversarial issues that may occur with the parents of the students with ASD because the parents will know that all legal and mandated supports their child deserves are being provided.

When the educational leader becomes aware of all the aspects of the legal information related to ASD, educational programming societal acceptance, care and respect of students are more likely to be enhanced at the school, and students will benefit to the fullest degree. Today's educational leaders can be one of the main facilitators of all of these benefits to students. By being pioneers and advocates in these areas, educational leaders can take educational programming to a new level and individualize curriculum while educating their staff members regarding differentiation of educational materials and needs within the classroom for students with ASD. This awareness among staff is critical so that there is uniformity and routine for students with ASD. This awareness can create

optimal carryover as well as safety and security so that students feel a sense of placement within their environment during their school experience. The educational leader can also help facilitate societal acceptance, care and respect for students with ASD by modeling it and setting the tone for how these students are treated in their educational facility. If the staff and students have heightened awareness of the differences that students with ASD possess, they are more apt to accept these differences and embrace them. This is very important for the students with ASD considering one of their main deficits is social communication. With societal acceptance, care and respect within the educational facility, these students can feel more comfortable to socialize with staff members and their peers, thereby increasing their exposure to socialization and increasing their opportunity to develop positive social relationships.

Recommendations for Further Research

There are several possibilities for further research that are closely related to this topic. This study is just a small sample of areas that need to be researched more thoroughly. One possibility would be to review how the transition period after high school has evolved for people with ASD, and how some of the areas discussed in this study have influenced the transition to post-secondary placements. A study could be initiated to highlight the importance of transition and its key parts related to the education process for people with ASD.

A second possibility could be studying the increase in awareness to ASD that has taken place over time. A study could be initiated considering information that has currently been appearing in the media concerning the increase in diagnosis of ASD, the

recent vaccination controversy pertaining to ASD or how influential people have been discussing ASD related to their family members. Some of these awareness factors influencing ASD have been mentioned in this study, but there are several other areas that have influenced awareness as well and could also be researched.

A final possibility would be to research how some of the areas discussed in this study have truly affected the educational environment over time. How have schools changed, and how have the roles of teachers and staff members changed because of the needs of the students with ASD.

Researcher's Reflection

Autism Spectrum Disorder (ASD) has truly become the researcher's passion during the 13 years of her career. The researcher has worked with ASD students who have touched her life and influenced who she is as a professional. By delving into the research of this study, the researcher gained considerable knowledge regarding the evolution of ASD. As an educational leader equipped with this knowledge, she will now be able to use, what she has learned to positively influence staff members, students and parents in improving educational experiences of individuals with ASD. With this positive influence, she will also be able to increase societal acceptance, care and respect for these students within her professional environment.

Epilogue

Events from 2013-2015

Since the ending of this research study, there have been events that have taken place concerning ASD. Below, highlights a few of these current events regarding ASD. It

is important to recognize some of these current events, since the historical perspective of this research study ended in 2013. From 2013 on until the present day 2015, some of the recent events, which have taken place in the specific areas that this research study has outlined, are as follows:

Medically:

- The controversy regarding vaccinations and the findings of Andrew Wakefield has been revisited.
- The usage of preservatives in vaccinations and their effects on babies is again in question.
- Prenatal care effecting or possibly being involved in the causation of ASD and the link to adequate folic acid and ASD is being researched.

Media:

- The ASD rate is 1 in 68 children.
- World Autism Day promoted ASD by asking major companies to turn their buildings and advertisements blue and asking celebrities to support ASD by wearing blue for awareness April, 2, 2013.
- Jerry Seinfeld claims he is on the spectrum of ASD, but quickly recants his comments.
- Measles outbreak at Disney World December-January 2015.
- Andrew Wakfield addressed the Measles outbreak of 2015.

APPENDIX A
IDEA-PART C

IDEA-PART C:

- **(C) INFANTS AND TODDLERS WITH DISABILITIES**

- **SEC. 631. FINDINGS AND POLICY.**

- (a) Findings.--Congress finds that there is an urgent and substantial need--
 - (1) to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life;
 - (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
 - (3) to maximize the potential for individuals with disabilities to live independently in society;
 - (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
 - (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.
 - (b) Policy.--It is the policy of the United States to provide financial assistance to States--
 - (1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families;
 - (2) to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage);
 - (3) to enhance State capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families; and
 - (4) to encourage States to expand opportunities for children under 3 years of age who would be at risk

of having substantial developmental delay if they did not receive early intervention services.

▪ **SEC. 632. DEFINITIONS.**

In this part:

- (1) At-risk infant or toddler.--The term `at-risk infant or toddler' means an individual under 3 years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual.
- (2) Council.--The term `council' means a State interagency coordinating council established under section 641.
- (3) Developmental delay.--The term `developmental delay', when used with respect to an individual residing in a State, has the meaning given such term by the State under section 635(a)(1).
- (4) Early intervention services.--The term `early intervention services' means developmental services that--
 - (A) are provided under public supervision;
 - (B) are provided at no cost except where Federal or State law provides for a system of payments by families, including a schedule of sliding fees;
 - (C) are designed to meet the developmental needs of an infant or toddler with a disability, as identified by the individualized family service plan team, in any 1 or more of the following areas:
 - (i) physical development;
 - (ii) cognitive development;
 - (iii) communication development;
 - (iv) social or emotional development; or
 - (v) adaptive development;
 - (D) meet the standards of the State in which the services are provided, including the requirements of this part;
 - (E) include--
 - (i) family training, counseling, and home visits;
 - (ii) special instruction;
 - (iii) speech-language pathology and audiology services, and sign language and cued language services;
 - (iv) occupational therapy;
 - (v) physical therapy;
 - (vi) psychological services;
 - (vii) service coordination services;

- (viii) medical services only for diagnostic or evaluation purposes;
 - (ix) early identification, screening, and assessment services;
 - (x) health services necessary to enable the infant or toddler to benefit from the other early intervention services;
 - (xi) social work services;
 - (xii) vision services;
 - (xiii) assistive technology devices and assistive technology services; and
 - (xiv) transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to receive another service described in this paragraph;
 - (F) are provided by qualified personnel, including--
 - (i) special educators;
 - (ii) speech-language pathologists and audiologists;
 - (iii) occupational therapists;
 - (iv) physical therapists;
 - (v) psychologists;
 - (vi) social workers;
 - (vii) nurses;
 - (viii) registered dietitians;
 - (ix) family therapists;
 - (x) vision specialists, including ophthalmologists and optometrists;
 - (xi) orientation and mobility specialists; and
 - (xii) pediatricians and other physicians;
 - (G) to the maximum extent appropriate, are provided in natural environments, including the home, and community settings in which children without disabilities participate; and
 - (H) are provided in conformity with an individualized family service plan adopted in accordance with section 636.
- (5) Infant or toddler with a disability.--The term 'infant or toddler with a disability'--
- (A) means an individual under 3 years of age who needs early intervention services because the individual--
 - (i) is experiencing developmental delays, as measured by appropriate diagnostic

instruments and procedures in 1 or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or

- (ii) has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay; and
- (B) may also include, at a State's discretion--
 - (i) at-risk infants and toddlers; and
 - (ii) children with disabilities who are eligible for services under section 619 and who previously received services under this part until such children enter, or are eligible under State law to enter, kindergarten or elementary school, as appropriate, provided that any programs under this part serving such children shall include--
 - (I) an educational component that promotes school readiness and incorporates pre-literacy, language, and numeracy skills; and
 - (II) a written notification to parents of their rights and responsibilities in determining whether their child will continue to receive services under this part or participate in preschool programs under section 619.
- **SEC. 633. GENERAL AUTHORITY.**
 The Secretary shall, in accordance with this part, make grants to States (from their allotments under section 643) to assist each State to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families.
- **SEC. 634. ELIGIBILITY.**
 In order to be eligible for a grant under section 633, a State shall provide assurances to the Secretary that the State--
 - (1) has adopted a policy that appropriate early intervention services are available to all infants and toddlers with disabilities in the State and their families, including Indian infants and toddlers with disabilities and their families residing on a reservation geographically located in the State, infants and toddlers with disabilities who are

homeless children and their families, and infants and toddlers with disabilities who are wards of the State; and

- (2) has in effect a statewide system that meets the requirements of section 635.

▪ **SEC. 635. REQUIREMENTS FOR STATEWIDE SYSTEM.**

- (a) In General.--A statewide system described in section 633 shall include, at a minimum, the following components:
 - (1) A rigorous definition of the term 'developmental delay' that will be used by the State in carrying out programs under this part in order to appropriately identify infants and toddlers with disabilities that are in need of services under this part.
 - (2) A State policy that is in effect and that ensures that appropriate early intervention services based on scientifically based research, to the extent practicable, are available to all infants and toddlers with disabilities and their families, including Indian infants and toddlers with disabilities and their families residing on a reservation geographically located in the State and infants and toddlers with disabilities who are homeless children and their families.
 - (3) A timely, comprehensive, multidisciplinary evaluation of the functioning of each infant or toddler with a disability in the State, and a family-directed identification of the needs of each family of such an infant or toddler, to assist appropriately in the development of the infant or toddler.
 - (4) For each infant or toddler with a disability in the State, an individualized family service plan in accordance with section 636, including service coordination services in accordance with such service plan.
 - (5) A comprehensive child find system, consistent with part B, including a system for making referrals to service providers that includes timelines and provides for participation by primary referral sources and that ensures rigorous standards for appropriately identifying infants and toddlers with disabilities for services under this part that will reduce the need for future services.
 - (6) A public awareness program focusing on early identification of infants and toddlers with

disabilities, including the preparation and dissemination by the lead agency designated or established under paragraph (10) to all primary referral sources, especially hospitals and physicians, of information to be given to parents, especially to inform parents with premature infants, or infants with other physical risk factors associated with learning or developmental complications, on the availability of early intervention services under this part and of services under section 619, and procedures for assisting such sources in disseminating such information to parents of infants and toddlers with disabilities.

- (7) A central directory that includes information on early intervention services, resources, and experts available in the State and research and demonstration projects being conducted in the State.
- (8) A comprehensive system of personnel development, including the training of paraprofessionals and the training of primary referral sources with respect to the basic components of early intervention services available in the State that--
 - (A) shall include--
 - (i) implementing innovative strategies and activities for the recruitment and retention of early education service providers;
 - (ii) promoting the preparation of early intervention providers who are fully and appropriately qualified to provide early intervention services under this part; and
 - (iii) training personnel to coordinate transition services for infants and toddlers served under this part from a program providing early intervention services under this part and under part B (other than section 619), to a preschool program receiving funds under section 619, or another appropriate program; and
 - (B) may include--

- (i) training personnel to work in rural and inner-city areas; and
 - (ii) training personnel in the emotional and social development of young children.
- (9) Policies and procedures relating to the establishment and maintenance of qualifications to ensure that personnel necessary to carry out this part are appropriately and adequately prepared and trained, including the establishment and maintenance of qualifications that are consistent with any State-approved or recognized certification, licensing, registration, or other comparable requirements that apply to the area in which such personnel are providing early intervention services, except that nothing in this part (including this paragraph) shall be construed to prohibit the use of paraprofessionals and assistants who are appropriately trained and supervised in accordance with State law, regulation, or written policy, to assist in the provision of early intervention services under this part to infants and toddlers with disabilities.
- (10) A single line of responsibility in a lead agency designated or established by the Governor for carrying out--
 - (A) the general administration and supervision of programs and activities receiving assistance under section 633, and the monitoring of programs and activities used by the State to carry out this part, whether or not such programs or activities are receiving assistance made available under section 633, to ensure that the State complies with this part;
 - (B) the identification and coordination of all available resources within the State from Federal, State, local, and private sources;
 - (C) the assignment of financial responsibility in accordance with section 637(a)(2) to the appropriate agencies;
 - (D) the development of procedures to ensure that services are provided to infants and toddlers with disabilities and their families

under this part in a timely manner pending the resolution of any disputes among public agencies or service providers;

- (E) the resolution of intra- and interagency disputes; and
- (F) the entry into formal interagency agreements that define the financial responsibility of each agency for paying for early intervention services (consistent with State law) and procedures for resolving disputes and that include all additional components necessary to ensure meaningful cooperation and coordination.
- (11) A policy pertaining to the contracting or making of other arrangements with service providers to provide early intervention services in the State, consistent with the provisions of this part, including the contents of the application used and the conditions of the contract or other arrangements.
- (12) A procedure for securing timely reimbursements of funds used under this part in accordance with section 640(a).
- (13) Procedural safeguards with respect to programs under this part, as required by section 639.
- (14) A system for compiling data requested by the Secretary under section 618 that relates to this part.
- (15) A State interagency coordinating council that meets the requirements of section 641.
- (16) Policies and procedures to ensure that, consistent with section 636(d)(5)--
 - (A) to the maximum extent appropriate, early intervention services are provided in natural environments; and
 - (B) the provision of early intervention services for any infant or toddler with a disability occurs in a setting other than a natural environment that is most appropriate, as determined by the parent and the individualized family service plan team, only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment.
- (b) Policy.--In implementing subsection (a)(9), a State may adopt a policy that includes making ongoing good-faith

efforts to recruit and hire appropriately and adequately trained personnel to provide early intervention services to infants and toddlers with disabilities, including, in a geographic area of the State where there is a shortage of such personnel, the most qualified individuals available who are making satisfactory progress toward completing applicable course work necessary to meet the standards described in subsection (a)(9).

- (c) Flexibility To Serve Children 3 Years of Age Until Entrance Into Elementary School.--
 - (1) In general.--A statewide system described in section 633 may include a State policy, developed and implemented jointly by the lead agency and the State educational agency, under which parents of children with disabilities who are eligible for services under section 619 and previously received services under this part, may choose the continuation of early intervention services (which shall include an educational component that promotes school readiness and incorporates preliteracy, language, and numeracy skills) for such children under this part until such children enter, or are eligible under State law to enter, kindergarten.
 - (2) Requirements.--If a statewide system includes a State policy described in paragraph (1), the statewide system shall ensure that--
 - (A) parents of children with disabilities served pursuant to this subsection are provided annual notice that contains--
 - (i) a description of the rights of such parents to elect to receive services pursuant to this subsection or under part B; and
 - (ii) an explanation of the differences between services provided pursuant to this subsection and services provided under part B, including--
 - (I) types of services and the locations at which the services are provided;
 - (II) applicable procedural safeguards; and
 - (III) possible costs (including any fees to be charged to

families as described in section 632(4)(B)), if any, to parents of infants or toddlers with disabilities;

- (B) services provided pursuant to this subsection include an educational component that promotes school readiness and incorporates preliteracy, language, and numeracy skills;
 - (C) the State policy will not affect the right of any child served pursuant to this subsection to instead receive a free appropriate public education under part B;
 - (D) all early intervention services outlined in the child's individualized family service plan under section 636 are continued while any eligibility determination is being made for services under this subsection;
 - (E) the parents of infants or toddlers with disabilities (as defined in section 632(5)(A)) provide informed written consent to the State, before such infants or toddlers reach 3 years of age, as to whether such parents intend to choose the continuation of early intervention services pursuant to this subsection for such infants or toddlers;
 - (F) the requirements under section 637(a)(9) shall not apply with respect to a child who is receiving services in accordance with this subsection until not less than 90 days (and at the discretion of the parties to the conference, not more than 9 months) before the time the child will no longer receive those services; and
 - (G) there will be a referral for evaluation for early intervention services of a child who experiences a substantiated case of trauma due to exposure to family violence (as defined in section 320 of the Family Violence Prevention and Services Act).
- (3) Reporting requirement.--If a statewide system includes a State policy described in paragraph (1), the State shall submit to the Secretary, in the State's report under section 637(b)(4)(A), a report on the

number and percentage of children with disabilities who are eligible for services under section 619 but whose parents choose for such children to continue to receive early intervention services under this part.

- (4) Available funds.--If a statewide system includes a State policy described in paragraph (1), the policy shall describe the funds (including an identification as Federal, State, or local funds) that will be used to ensure that the option described in paragraph (1) is available to eligible children and families who provide the consent described in paragraph (2)(E), including fees (if any) to be charged to families as described in section 632(4)(B).
- (5) Rules of construction.--
 - (A) Services under part b.--If a statewide system includes a State policy described in paragraph (1), a State that provides services in accordance with this subsection to a child with a disability who is eligible for services under section 619 shall not be required to provide the child with a free appropriate public education under part B for the period of time in which the child is receiving services under this part.
 - (B) Services under this part.--Nothing in this subsection shall be construed to require a provider of services under this part to provide a child served under this part with a free appropriate public education.
- **SEC. 636. INDIVIDUALIZED FAMILY SERVICE PLAN.**
 - (a) Assessment and Program Development.--A statewide system described in section 633 shall provide, at a minimum, for each infant or toddler with a disability, and the infant's or toddler's family, to receive--
 - (1) a multidisciplinary assessment of the unique strengths and needs of the infant or toddler and the identification of services appropriate to meet such needs;
 - (2) a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler; and

- (3) a written individualized family service plan developed by a multidisciplinary team, including the parents, as required by subsection (e), including a description of the appropriate transition services for the infant or toddler.
- (b) Periodic Review.--The individualized family service plan shall be evaluated once a year and the family shall be provided a review of the plan at 6-month intervals (or more often where appropriate based on infant or toddler and family needs).
- (c) Promptness After Assessment.--The individualized family service plan shall be developed within a reasonable time after the assessment required by subsection (a)(1) is completed. With the parents' consent, early intervention services may commence prior to the completion of the assessment.
- (d) Content of Plan.--The individualized family service plan shall be in writing and contain--
 - (1) a statement of the infant's or toddler's present levels of physical development, cognitive development, communication development, social or emotional development, and adaptive development, based on objective criteria;
 - (2) a statement of the family's resources, priorities, and concerns relating to enhancing the development of the family's infant or toddler with a disability;
 - (3) a statement of the measurable results or outcomes expected to be achieved for the infant or toddler and the family, including pre-literacy and language skills, as developmentally appropriate for the child, and the criteria, procedures, and timelines used to determine the degree to which progress toward achieving the results or outcomes is being made and whether modifications or revisions of the results or outcomes or services are necessary;
 - (4) a statement of specific early intervention services based on peer-reviewed research, to the extent practicable, necessary to meet the unique needs of the infant or toddler and the family, including the frequency, intensity, and method of delivering services;
 - (5) a statement of the natural environments in which early intervention services will appropriately be provided, including a justification of the extent, if

any, to which the services will not be provided in a natural environment;

- (6) the projected dates for initiation of services and the anticipated length, duration, and frequency of the services;
- (7) the identification of the service coordinator from the profession most immediately relevant to the infant's or toddler's or family's needs (or who is otherwise qualified to carry out all applicable responsibilities under this part) who will be responsible for the implementation of the plan and coordination with other agencies and persons, including transition services; and
- (8) the steps to be taken to support the transition of the toddler with a disability to preschool or other appropriate services.
- (e) Parental Consent.--The contents of the individualized family service plan shall be fully explained to the parents and informed written consent from the parents shall be obtained prior to the provision of early intervention services described in such plan. If the parents do not provide consent with respect to a particular early intervention service, then only the early intervention services to which consent is obtained shall be provided.
- **SEC. 637. STATE APPLICATION AND ASSURANCES.**
 - (a) Application.--A State desiring to receive a grant under section 633 shall submit an application to the Secretary at such time and in such manner as the Secretary may reasonably require. The application shall contain--
 - (1) a designation of the lead agency in the State that will be responsible for the administration of funds provided under section 633;
 - (2) a certification to the Secretary that the arrangements to establish financial responsibility for services provided under this part pursuant to section 640(b) are current as of the date of submission of the certification;
 - (3) information demonstrating eligibility of the State under section 634, including--
 - (A) information demonstrating to the Secretary's satisfaction that the State has in effect the statewide system required by section 633; and

- (B) a description of services to be provided to infants and toddlers with disabilities and their families through the system;
- (4) if the State provides services to at-risk infants and toddlers through the statewide system, a description of such services;
- (5) a description of the uses for which funds will be expended in accordance with this part;
- (6) a description of the State policies and procedures that require the referral for early intervention services under this part of a child under the age of 3 who--
 - (A) is involved in a substantiated case of child abuse or neglect; or
 - (B) is identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure;
- (7) a description of the procedure used to ensure that resources are made available under this part for all geographic areas within the State;
- (8) a description of State policies and procedures that ensure that, prior to the adoption by the State of any other policy or procedure necessary to meet the requirements of this part, there are public hearings, adequate notice of the hearings, and an opportunity for comment available to the general public, including individuals with disabilities and parents of infants and toddlers with disabilities;
- (9) a description of the policies and procedures to be used--
 - (A) to ensure a smooth transition for toddlers receiving early intervention services under this part (and children receiving those services under section 635(c)) to preschool, school, other appropriate services, or exiting the program, including a description of how--
 - (i) the families of such toddlers and children will be included in the transition plans required by subparagraph (C); and
 - (ii) the lead agency designated or established under section 635(a)(10) will--

- (I) notify the local educational agency for the area in which such a child resides that the child will shortly reach the age of eligibility for preschool services under part B, as determined in accordance with State law;
- (II) in the case of a child who may be eligible for such preschool services, with the approval of the family of the child, convene a conference among the lead agency, the family, and the local educational agency not less than 90 days (and at the discretion of all such parties, not more than 9 months) before the child is eligible for the preschool services, to discuss any such services that the child may receive; and
- (III) in the case of a child who may not be eligible for such preschool services, with the approval of the family, make reasonable efforts to convene a conference among the lead agency, the family, and providers of other appropriate services for children who are not eligible for preschool services under part B, to discuss the appropriate services that the child may receive;
- (B) to review the child's program options for the period from the child's third birthday through the remainder of the school year; and

- (C) to establish a transition plan, including, as appropriate, steps to exit from the program;
 - (10) a description of State efforts to promote collaboration among Early Head Start programs under section 645A of the Head Start Act, early education and child care programs, and services under part C; and
 - (11) such other information and assurances as the Secretary may reasonably require.
- (b) Assurances.--The application described in subsection (a)--
 - (1) shall provide satisfactory assurance that Federal funds made available under section 643 to the State will be expended in accordance with this part;
 - (5) provide satisfactory assurance that Federal funds made available under section 643 to the State--
 - (A) will not be commingled with State funds; and
 - (B) will be used so as to supplement the level of State and local funds expended for infants and toddlers with disabilities and their families and in no case to supplant those State and local funds;
 - (6) shall provide satisfactory assurance that such fiscal control and fund accounting procedures will be adopted as may be necessary to ensure proper disbursement of, and accounting for, Federal funds paid under section 643 to the State;
 - (7) shall provide satisfactory assurance that policies and procedures have been adopted to ensure meaningful involvement of underserved groups, including minority, low-income, homeless, and rural families and children with disabilities who are wards of the State, in the planning and implementation of all the requirements of this part; and
 - (8) shall contain such other information and assurances as the Secretary may reasonably require by regulation.
 - (2) shall contain an assurance that the State will comply with the requirements of section 640;
 - (3) shall provide satisfactory assurance that the control of funds provided under section 643, and

title to property derived from those funds, will be in a public agency for the uses and purposes provided in this part and that a public agency will administer such funds and property;

- (4) shall provide for--
 - (B) keeping such reports and affording such access to the reports as the Secretary may find necessary to ensure the correctness and verification of those reports and proper disbursement of Federal funds under this part;
 - (A) making such reports in such form and containing such information as the Secretary may require to carry out the Secretary's functions under this part; and
- (c) Standard for Disapproval of Application.--The Secretary may not disapprove such an application unless the Secretary determines, after notice and opportunity for a hearing, that the application fails to comply with the requirements of this section.
- (d) Subsequent State Application.--If a State has on file with the Secretary a policy, procedure, or assurance that demonstrates that the State meets a requirement of this section, including any policy or procedure filed under this part (as in effect before the date of enactment of the Individuals with Disabilities Education Improvement Act of 2004), the Secretary shall consider the State to have met the requirement for purposes of receiving a grant under this part.
- (e) Modification of Application.--An application submitted by a State in accordance with this section shall remain in effect until the State submits to the Secretary such modifications as the State determines necessary. This section shall apply to a modification of an application to the same extent and in the same manner as this section applies to the original application.
- (f) Modifications Required by the Secretary.--The Secretary may require a State to modify its application under this section, but only to the extent necessary to ensure the State's compliance with this part, if--
 - (1) an amendment is made to this title, or a Federal regulation issued under this title;
 - (2) a new interpretation of this title is made by a Federal court or the State's highest court; or

- (3) an official finding of noncompliance with Federal law or regulations is made with respect to the State.

▪ **SEC. 638. USES OF FUNDS.**

In addition to using funds provided under section 633 to maintain and implement the statewide system required by such section, a State may use such funds--

- (1) for direct early intervention services for infants and toddlers with disabilities, and their families, under this part that are not otherwise funded through other public or private sources;
 - (2) to expand and improve on services for infants and toddlers and their families under this part that are otherwise available;
 - (3) to provide a free appropriate public education, in accordance with part B, to children with disabilities from their third birthday to the beginning of the following school year;
 - (4) with the written consent of the parents, to continue to provide early intervention services under this part to children with disabilities from their 3rd birthday until such children enter, or are eligible under State law to enter, kindergarten, in lieu of a free appropriate public education provided in accordance with part B; and
 - (5) in any State that does not provide services for at-risk infants and toddlers under section 637(a)(4), to strengthen the statewide system by initiating, expanding, or improving collaborative efforts related to at-risk infants and toddlers, including establishing linkages with appropriate public or private community-based organizations, services, and personnel for the purposes of--
 - (A) identifying and evaluating at-risk infants and toddlers;
 - (B) making referrals of the infants and toddlers identified and evaluated under subparagraph (A); and
 - (C) conducting periodic follow-up on each such referral to determine if the status of the infant or toddler involved has changed with respect to the eligibility of the infant or toddler for services under this part.

▪ **SEC. 639. PROCEDURAL SAFEGUARDS.**

- (a) Minimum Procedures.--The procedural safeguards required to be included in a statewide system under section 635(a)(13) shall provide, at a minimum, the following:
 - (1) The timely administrative resolution of complaints by parents. Any party aggrieved by the findings and decision regarding an administrative complaint shall have the right to bring a civil action with respect to the complaint in any State court of competent jurisdiction or in a district court of the United States without regard to the amount in controversy. In any action brought under this paragraph, the court shall receive the records of the administrative proceedings, shall hear additional evidence at the request of a party, and, basing its decision on the preponderance of the evidence, shall grant such relief as the court determines is appropriate.
 - (2) The right to confidentiality of personally identifiable information, including the right of parents to written notice of and written consent to the exchange of such information among agencies consistent with Federal and State law.
 - (3) The right of the parents to determine whether they, their infant or toddler, or other family members will accept or decline any early intervention service under this part in accordance with State law without jeopardizing other early intervention services under this part.
 - (4) The opportunity for parents to examine records relating to assessment, screening, eligibility determinations, and the development and implementation of the individualized family service plan.
 - (5) Procedures to protect the rights of the infant or toddler whenever the parents of the infant or toddler are not known or cannot be found or the infant or toddler is a ward of the State, including the assignment of an individual (who shall not be an employee of the State lead agency, or other State agency, and who shall not be any person, or any employee of a person, providing early intervention services to the infant or toddler or any family

member of the infant or toddler) to act as a surrogate for the parents.

- (6) Written prior notice to the parents of the infant or toddler with a disability whenever the State agency or service provider proposes to initiate or change, or refuses to initiate or change, the identification, evaluation, or placement of the infant or toddler with a disability, or the provision of appropriate early intervention services to the infant or toddler.
- (7) Procedures designed to ensure that the notice required by paragraph (6) fully informs the parents, in the parents' native language, unless it clearly is not feasible to do so, of all procedures available pursuant to this section.
- (8) The right of parents to use mediation in accordance with section 615, except that--
 - (A) any reference in the section to a State educational agency shall be considered to be a reference to a State's lead agency established or designated under section 635(a)(10);
 - (B) any reference in the section to a local educational agency shall be considered to be a reference to a local service provider or the State's lead agency under this part, as the case may be; and
 - (C) any reference in the section to the provision of a free appropriate public education to children with disabilities shall be considered to be a reference to the provision of appropriate early intervention services to infants and toddlers with disabilities.
- (b) Services During Pendency of Proceedings.--During the pendency of any proceeding or action involving a complaint by the parents of an infant or toddler with a disability, unless the State agency and the parents otherwise agree, the infant or toddler shall continue to receive the appropriate early interventionservices currently being provided or, if applying for initial services, shall receive the services not in dispute.

▪ **SEC. 640. PAYOR OF LAST RESORT.**

- (a) Nonsubstitution.--Funds provided under section 643 may not be used to satisfy a financial commitment for services that would have been paid for from another public or private source, including any medical program administered by the Secretary of Defense, but for the enactment of this part, except that whenever considered necessary to prevent a delay in the receipt of appropriate early intervention services by an infant, toddler, or family in a timely fashion, funds provided under section 643 may be used to pay the provider of services pending reimbursement from the agency that has ultimate responsibility for the payment.
- (b) Obligations Related to and Methods of Ensuring Services.--
 - (1) Establishing financial responsibility for services.--
 - (A) In general.--The Chief Executive Officer of a State or designee of the officer shall ensure that an interagency agreement or other mechanism for interagency coordination is in effect between each public agency and the designated lead agency, in order to ensure--
 - (i) the provision of, and financial responsibility for, services provided under this part; and
 - (ii) such services are consistent with the requirements of section 635 and the State's application pursuant to section 637, including the provision of such services during the pendency of any such dispute.
 - (B) Consistency between agreements or mechanisms under part b.--The Chief Executive Officer of a State or designee of the officer shall ensure that the terms and conditions of such agreement or mechanism are consistent with the terms and conditions of the State's agreement or mechanism under section 612(a)(12), where appropriate.
 - (2) Reimbursement for services by public agency.--
 - (A) In general.--If a public agency other than an educational agency fails to provide

or pay for the services pursuant to an agreement required under paragraph (1), the local educational agency or State agency (as determined by the Chief Executive Officer or designee) shall provide or pay for the provision of such services to the child.

- (B) Reimbursement.--Such local educational agency or State agency is authorized to claim reimbursement for the services from the public agency that failed to provide or pay for such services and such public agency shall reimburse the local educational agency or State agency pursuant to the terms of the interagency agreement or other mechanism required under paragraph (1).
- (3) Special rule.--The requirements of paragraph (1) may be met through--
 - (A) State statute or regulation;
 - (B) signed agreements between respective agency officials that clearly identify the responsibilities of each agency relating to the provision of services; or
 - (C) other appropriate written methods as determined by the Chief Executive Officer of the State or designee of the officer and approved by the Secretary through the review and approval of the State's application pursuant to section 637.
- (c) Reduction of Other Benefits.--Nothing in this part shall be construed to permit the State to reduce medical or other assistance available or to alter eligibility under title V of the Social Security Act (relating to maternal and child health) or title XIX of the Social Security Act (relating to medicaid for infants or toddlers with disabilities) within the State.
- **SEC. 641. STATE INTERAGENCY COORDINATING COUNCIL.**
 - (a) Establishment.--
 - (1) In general.--A State that desires to receive financial assistance under this part shall establish a State interagency coordinating council.
 - (2) Appointment.--The council shall be appointed by the Governor. In making appointments to the council, the Governor shall ensure that the

membership of the council reasonably represents the population of the State.

- (3) Chairperson.--The Governor shall designate a member of the council to serve as the chairperson of the council, or shall require the council to so designate such a member. Any member of the council who is a representative of the lead agency designated under section 635(a)(10) may not serve as the chairperson of the council.
- (b) Composition.--
 - (1) In general.--The council shall be composed as follows:
 - (A) Parents.--Not less than 20 percent of the members shall be parents of infants or toddlers with disabilities or children with disabilities aged 12 or younger, with knowledge of, or experience with, programs for infants and toddlers with disabilities. Not less than 1 such member shall be a parent of an infant or toddler with a disability or a child with a disability aged 6 or younger.
 - (B) Service providers.--Not less than 20 percent of the members shall be public or private providers of early intervention services.
 - (C) State legislature.--Not less than 1 member shall be from the State legislature.
 - (D) Personnel preparation.--Not less than 1 member shall be involved in personnel preparation.
 - (E) Agency for early intervention services.--Not less than 1 member shall be from each of the State agencies involved in the provision of, or payment for, early intervention services to infants and toddlers with disabilities and their families and shall have sufficient authority to engage in policy planning and implementation on behalf of such agencies.
 - (F) Agency for preschool services.--Not less than 1 member shall be from the State educational agency responsible for preschool services to children with disabilities and shall have sufficient

authority to engage in policy planning and implementation on behalf of such agency.

- (G) State medicaid agency.--Not less than 1 member shall be from the agency responsible for the State medicaid program.
- (H) Head start agency.--Not less than 1 member shall be a representative from a Head Start agency or program in the State.
 - (I) Child care agency.--Not less than 1 member shall be a representative from a State agency responsible for child care.
- (J) Agency for health insurance.--Not less than 1 member shall be from the agency responsible for the State regulation of health insurance.
- (K) Office of the coordinator of education of homeless children and youth.--Not less than 1 member shall be a representative designated by the Office of Coordinator for Education of Homeless Children and Youths.
- (L) State foster care representative.--Not less than 1 member shall be a representative from the State child welfare agency responsible for foster care.
- (M) Mental health agency.--Not less than 1 member shall be a representative from the State agency responsible for children's mental health.
- (2) Other members.--The council may include other members selected by the Governor, including a representative from the Bureau of Indian Affairs (BIA), or where there is no BIA- operated or BIA-funded school, from the Indian Health Service or the tribe or tribal council.
- (c) Meetings.--The council shall meet, at a minimum, on a quarterly basis, and in such places as the council determines necessary. The meetings shall be publicly announced, and, to the extent appropriate, open and accessible to the general public.
- (d) Management Authority.--Subject to the approval of the Governor, the council may prepare and approve a budget using funds under this part to conduct hearings and forums,

to reimburse members of the council for reasonable and necessary expenses for attending council meetings and performing council duties (including child care for parent representatives), to pay compensation to a member of the council if the member is not employed or must forfeit wages from other employment when performing official council business, to hire staff, and to obtain the services of such professional, technical, and clerical personnel as may be necessary to carry out its functions under this part.

- (e) Functions of Council.--
 - (1) Duties.--The council shall--
 - (A) advise and assist the lead agency designated or established under section 635(a)(10) in the performance of the responsibilities set forth in such section, particularly the identification of the sources of fiscal and other support for services for early intervention programs, assignment of financial responsibility to the appropriate agency, and the promotion of the interagency agreements;
 - (B) advise and assist the lead agency in the preparation of applications and amendments thereto;
 - (C) advise and assist the State educational agency regarding the transition of toddlers with disabilities to preschool and other appropriate services; and
 - (D) prepare and submit an annual report to the Governor and to the Secretary on the status of early intervention programs for infants and toddlers with disabilities and their families operated within the State.
 - (2) Authorized activity.--The council may advise and assist the lead agency and the State educational agency regarding the provision of appropriate services for children from birth through age 5. The council may advise appropriate agencies in the State with respect to the integration of services for infants and toddlers with disabilities and at-risk infants and toddlers and their families, regardless of whether at-risk infants and toddlers are eligible for early intervention services in the State.

- (f) Conflict of Interest.--No member of the council shall cast a vote on any matter that is likely to provide a direct financial benefit to that member or otherwise give the appearance of a conflict of interest under State law.
- **SEC. 642. FEDERAL ADMINISTRATION.**

Sections 616, 617, and 618 shall, to the extent not inconsistent with this part, apply to the program authorized by this part, except that--

- (1) any reference in such sections to a State educational agency shall be considered to be a reference to a State's lead agency established or designated under section 635(a)(10);
 - (2) any reference in such sections to a local educational agency, educational service agency, or a State agency shall be considered to be a reference to an early intervention service provider under this part; and
 - (3) any reference to the education of children with disabilities or the education of all children with disabilities shall be considered to be a reference to the provision of appropriate early intervention services to infants and toddlers with disabilities.
- **SEC. 643. ALLOCATION OF FUNDS.**
 - (a) Reservation of Funds for Outlying Areas.--
 - (1) In general.--From the sums appropriated to carry out this part for any fiscal year, the Secretary may reserve not more than 1 percent for payments to Guam, American Samoa, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands in accordance with their respective needs for assistance under this part.
 - (2) Consolidation of funds.--The provisions of Public Law 95-134, permitting the consolidation of grants to the outlying areas, shall not apply to funds those areas receive under this part.
 - (b) Payments to Indians.--
 - (1) In general.--The Secretary shall, subject to this subsection, make payments to the Secretary of the Interior to be distributed to tribes, tribal organizations (as defined under section 4 of the Indian Self-Determination and Education Assistance Act), or consortia of the above entities for the coordination of assistance in the provision of

early intervention services by the States to infants and toddlers with disabilities and their families on reservations served by elementary schools and secondary schools for Indian children operated or funded by the Department of the Interior. The amount of such payment for any fiscal year shall be 1.25 percent of the aggregate of the amount available to all States under this part for such fiscal year.

- (2) Allocation.--For each fiscal year, the Secretary of the Interior shall distribute the entire payment received under paragraph (1) by providing to each tribe, tribal organization, or consortium an amount based on the number of infants and toddlers residing on the reservation, as determined annually, divided by the total of such children served by all tribes, tribal organizations, or consortia.
- (3) Information.--To receive a payment under this subsection, the tribe, tribal organization, or consortium shall submit such information to the Secretary of the Interior as is needed to determine the amounts to be distributed under paragraph (2).
- (4) Use of funds.--The funds received by a tribe, tribal organization, or consortium shall be used to assist States in child find, screening, and other procedures for the early identification of Indian children under 3 years of age and for parent training. Such funds may also be used to provide early intervention services in accordance with this part. Such activities may be carried out directly or through contracts or cooperative agreements with the Bureau of Indian Affairs, local educational agencies, and other public or private nonprofit organizations. The tribe, tribal organization, or consortium is encouraged to involve Indian parents in the development and implementation of these activities. The above entities shall, as appropriate, make referrals to local, State, or Federal entities for the provision of services or further diagnosis.
- (5) Reports.--To be eligible to receive a payment under paragraph (2), a tribe, tribal organization, or consortium shall make a biennial report to the Secretary of the Interior of activities undertaken under this subsection, including the number of

contracts and cooperative agreements entered into, the number of infants and toddlers contacted and receiving services for each year, and the estimated number of infants and toddlers needing services during the 2 years following the year in which the report is made. The Secretary of the Interior shall include a summary of this information on a biennial basis to the Secretary of Education along with such other information as required under section 611(h)(3)(E). The Secretary of Education may require any additional information from the Secretary of the Interior.

- (6) Prohibited uses of funds.--None of the funds under this subsection may be used by the Secretary of the Interior for administrative purposes, including child count, and the provision of technical assistance.
- (c) State Allotments.--
 - (1) In general.--Except as provided in paragraphs (2) and (3), from the funds remaining for each fiscal year after the reservation and payments under subsections (a), (b), and (e), the Secretary shall first allot to each State an amount that bears the same ratio to the amount of such remainder as the number of infants and toddlers in the State bears to the number of infants and toddlers in all States.
 - (2) Minimum allotments.--Except as provided in paragraph (3), no State shall receive an amount under this section for any fiscal year that is less than the greater of--
 - (A) $\frac{1}{2}$ of 1 percent of the remaining amount described in paragraph (1); or
 - (B) \$500,000.
 - (3) Ratable reduction.--
 - (A) In general.--If the sums made available under this part for any fiscal year are insufficient to pay the full amounts that all States are eligible to receive under this subsection for such year, the Secretary shall ratably reduce the allotments to such States for such year.
 - (B) Additional funds.--If additional funds become available for making payments under this subsection for a fiscal year,

allotments that were reduced under subparagraph (A) shall be increased on the same basis the allotments were reduced.

- (4) Definitions.--In this subsection--
 - (A) the terms 'infants' and 'toddlers' mean children under 3 years of age; and
 - (B) the term 'State' means each of the 50 States, the District of Columbia, and the Commonwealth of Puerto Rico.
- (d) Reallotment of Funds.--If a State elects not to receive its allotment under subsection (c), the Secretary shall reallot, among the remaining States, amounts from such State in accordance with such subsection.
- (e) Reservation for State Incentive Grants.--
 - (1) In general.--For any fiscal year for which the amount appropriated pursuant to the authorization of appropriations under section 644 exceeds \$460,000,000, the Secretary shall reserve 15 percent of such appropriated amount to provide grants to States that are carrying out the policy described in section 635(c) in order to facilitate the implementation of such policy.
 - (2) Amount of grant.--
 - (A) In general.--Notwithstanding paragraphs (2) and (3) of subsection (c), the Secretary shall provide a grant to each State under paragraph (1) in an amount that bears the same ratio to the amount reserved under such paragraph as the number of infants and toddlers in the State bears to the number of infants and toddlers in all States receiving grants under such paragraph.
 - (B) Maximum amount.--No State shall receive a grant under paragraph (1) for any fiscal year in an amount that is greater than 20 percent of the amount reserved under such paragraph for the fiscal year.
 - (3) Carryover of amounts.--
 - (A) First succeeding fiscal year.--Pursuant to section 421(b) of the General Education Provisions Act, amounts under a grant provided under paragraph (1) that are not obligated and expended prior to the beginning of the first fiscal year succeeding

the fiscal year for which such amounts were appropriated shall remain available for obligation and expenditure during such first succeeding fiscal year.

- (B) Second succeeding fiscal year.--
Amounts under a grant provided under paragraph (1) that are not obligated and expended prior to the beginning of the second fiscal year succeeding the fiscal year for which such amounts were appropriated shall be returned to the Secretary and used to make grants to States under section 633 (from their allotments under this section) during such second succeeding fiscal year.

▪ **SEC. 644. AUTHORIZATION OF APPROPRIATIONS.**

For the purpose of carrying out this part, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2005 through 2010.

APPENDIX B
OLMSTEAD V. L.C.

Olmstead v. L.C., pp. 12-18

“(a) The integration and reasonable-modifications regulations issued by the Attorney General rest on two key determinations: (1) Unjustified placement or retention of persons in institutions severely limits their exposure to the outside community, and therefore constitutes a form of discrimination based on disability prohibited by Title II, and (2) qualifying their obligation to avoid unjustified isolation of individuals with disabilities, States can resist modifications that would fundamentally alter the nature of their services and programs. The Eleventh Circuit essentially upheld the Attorney General’s construction of the ADA. This Court affirms the Court of Appeals decision in substantial part. pp. 11-12.

(b) Undue institutionalization qualifies as discrimination “by reason of ... disability.” The Department of Justice has consistently advocated that it does. Because the Department is the agency directed by Congress to issue Title II regulations, its views warrant respect. This Court need not inquire whether the degree of deference described in *Chevron U.S. A. Inc. v. Natural Resources Defense Council, Inc.*, 467 U.S. 837, 844, is in order; the well-reasoned views of the agencies implementing a statute constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance. *e.g.*, *Bragdon v. Abbott*, 524 U.S. 624, 642.

According to the State, L. C. and E. W. encountered no discrimination “by reason of” their disabilities because they were not denied community placement on account of those disabilities, nor were they subjected to “discrimination,” for they identified no comparison class of similarly situated individuals given preferential treatment. In rejecting these positions, the Court recognizes that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA. The ADA stepped up earlier efforts in the Developmentally Disabled Assistance and Bill of Rights Act the Rehabilitation Act of 1973 to secure opportunities for people with developmental disabilities to enjoy the benefits of community living. The ADA both requires all public entities to refrain from discrimination, see §12132, and specifically identifies unjustified “segregation” of persons with disabilities as a “for[m] of discrimination,” see §§12101(a)(2), 12101(a)(5). The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, cf., *e.g.*, *Allen v. Wright*, 468 U.S. 737, 755;

and institutional confinement severely diminishes individuals' everyday life activities. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice. The State correctly uses the past tense to frame its argument that, despite Congress' ADA findings, the Medicaid statute "reflected" a congressional policy preference for institutional treatment over treatment in the community. Since 1981, Medicaid has in fact provided funding for state-run home and community-based care through a waiver program. This Court emphasizes that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. In this case, however, it is not genuinely disputed that L. C. and E. W. are individuals "qualified" for noninstitutional care: The State's own professionals determined

that community-based treatment would be appropriate for L. C.
and E. W., and neither woman opposed such treatment.

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VITA

Cynthia Sikora is the daughter of Raymond and Barbara Reiplinger. She was born in Hammond, Indiana on January 3, 1978. She currently resides in a suburb of Chicago with her husband and three children.

Cynthia attended school in Lansing, Illinois during her elementary and middle school years and attended high school at Marion Catholic in Chicago Heights, Illinois. During her sophomore year of high school, her family moved to Munster, Indiana. She graduated from Purdue University in 2000 with a Bachelor of Science degree in Speech, Language and Hearing Sciences. In 2002, Cynthia earned a Master of Science degree in Communication Sciences and Disorders from Saint Xavier University. In 2005, Cynthia earned a Master of Arts degree in Administration and Supervision and a Type 75 administrative certificate from Governors State University.

Cynthia Sikora has been employed at Lincoln-Way High School District 210 for the past 13 years as a Speech-Language Pathologist. She has also been a Dean of Students and has served as a mentor and sponsor of various activities. A doctoral degree has been a lifelong goal for this educator.

DISSERTATION COMMITTEE

The dissertation submitted by Cynthia Sikora has been read and approved by the following committee:

Janis Fine, Ph.D., Director
Associate Professor, School of Education
Loyola University Chicago

Marla Israel, Ed.D.
Associate Professor, School of Education
Loyola University Chicago

James D. Upchurch, Ed.D.
Dean, College of Arts and Sciences
Olivet Nazarene University